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Pushing On: A Grounded Theory Study of Maternal Perinatal Bereavement.

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LOYOLA UNIVERSITY CHICAGO

PUSHING ON: A GROUNDED THEORY STUDY
OF MATERNAL PERINATAL BEREAVEMENT

A DISSERTATION SUBMITTED TO
THE FACULTY OF THE GRADUATE SCHOOL
IN CANDIDACY FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY

PROGRAM IN NURSING

BY
PATRICIA MOYLE WRIGHT

CHICAGO, ILLINOIS

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Dedicated in loving memory of my grandmothers,
Mary E. Moyle and Mary Kosar,
both of whom were bereaved mothers.

And, for M.C., a very special angel baby
with gratitude to her family.

Have compassion on those who suffer from any grief or trouble;
That they may be delivered from their distress.

The Book of Common Prayer (1979, p. 387)

TABLE OF CONTENTS

ACKNOWLEDGEMENTS	iii
LIST OF TABLES	ix
LIST OF FIGURES	x
ABSTRACT	xi
CHAPTER ONE: INTRODUCTION	1
Inconsistencies	2
Disparities	8
Gaps in the Perinatal Grief Literature	12
Purpose of the Study	14
Definition of Terms	14
Summary	14
CHAPTER TWO: REVIEW OF LITERATURE	16
Women's Responses to Pregnancy Loss	16
Influences on Maternal Responses to Pregnancy Loss	22
Summary	26
CHAPTER THREE: METHODOLOGY	29
Research Approach	29
Protection of Human Subjects	31
Data Collection	33
Data Analysis	33
Judging a Grounded Theory Study	34
Summary	35
CHAPTER FOUR: RESULTS	36
Sample	37
Recruitment	38
Data Collection and Analysis	38
Findings	42
Assessing Veracity	93
CHAPTER V: DISCUSSION	97
Storyline	97
Core Category	99
Stages	99
Unique Findings	111
Strengths and Limitations	113

Implications for Nursing Practice and Nursing Education	114
Implications for Future Research	116
APPENDIX A: LETTERS OF APPROVAL	118
APPENDIX B: RECRUITMENT MATERIALS	124
APPENDIX C: PARTICIPANT FORMS	128
REFERENCES	135
VITA	145

LIST OF TABLES

Table	Page
1. Definitions of Terms Used in Studies of Pregnancy and Infant Loss	3
2. Taxonomy of the Maternal Perinatal Bereavement Theory: Pushing On	92

LIST OF FIGURES

Figure 1	Page
Five stages of the substantive theory.	43

ABSTRACT

Over 1 million American women experience the unexpected loss of a pregnancy each year (Ventura, Abma, Mosher, & Henshaw, 2009). The care and support they receive from family members, friends, and health care providers is often inadequate. Despite nearly 3 decades of research, very little is known about women's experiences of loss and the trajectory of perinatal bereavement. This classic grounded theory study was undertaken to discover a substantive theory of maternal perinatal bereavement, which was empirically derived from the words of the participants.

Data were collected from interviews with 19 women who had experienced the loss of a pregnancy, and analyzed using the classic grounded theory method. Results indicated that maternal perinatal bereavement follows a 5-stage pattern that involves experiencing the pregnancy, losing the baby, bearing the burden, working through the pain, and transcending the suffering. Each of these stages involves several subprocesses that were derived from the data. The core category, which explains most of the action in the theory, was named "pushing on" and describes how the women managed to move beyond the overwhelming pain of the loss and eventually experience transcendence.

Findings of this study help unify and explain previous research by providing an empirically derived depiction of the pathway through maternal perinatal bereavement. The results of this study are useful for education purposes, developing future research studies on perinatal bereavement, policy making, and advocacy for bereaved mothers.

CHAPTER ONE:

INTRODUCTION

Becoming a mother is a dream for many women, and the news of a pregnancy is typically met with joyful anticipation. But, every year, over 1 million American women (Saraiya, Berg, Shulman, Green, & Atrash, 1999; Ventura, Abma, Mosher, & Henshaw, 2009) suffer the loss of an expected child. The American Pregnancy Association (2007) estimated that about 20% of pregnancies end unexpectedly prior to the 20th week of gestation, with the majority occurring before 13 weeks. The actual number of pregnancy losses occurring annually may be underestimated because only clinically diagnosed pregnancies are recognized (Wright, 2005).

Despite the frequency of pregnancy loss, research does not provide adequate information for health care providers to provide evidence based care to mothers at the time of loss, or empirically-derived information regarding maternal responses to pregnancy loss. In fact, a review of the research on pregnancy loss reveals a field that is fraught with inconsistent terminology, conflicting research findings, the application of outdated theories to clinical care, and a lack of evidence-based practice. These issues are important because they are reflected in health care providers' attitudes regarding pregnancy loss and their responses to bereaved women. This harrowing experience is often a burden that is carried silently throughout a woman's life. Nurses and others who

work with women immediately following a perinatal loss and in the subsequent weeks and months are often unaware of the significance of the loss to bereaved women.

Nursing care provided for women following pregnancy loss can and must be improved. Recommendations for the care of women following pregnancy loss have focused primarily on women's health settings, such as obstetric clinics or maternal-child units, but a clear understanding of the impact of pregnancy loss is vital for all nurses in all practice settings because pregnancy loss can haunt women for many years (Dyson & While, 1998). In most clinical settings, nurses routinely record women's reproductive history, including prior pregnancies, miscarriages, or planned abortions. Assessment of women's emotional responses to pregnancy loss is not generally expected or gathered, but such information is important to understanding how women cope with loss.

Issues that affect health care providers' understanding of pregnancy loss, such as inconsistent terminology, and disparity between theory and evidence are discussed in this chapter. The lack of evidence-based practice recommendations and the effects of current practices on bereaved mothers are reviewed. The chapter concludes with a discussion of how nursing care of women following pregnancy loss can be improved through research.

Inconsistencies

Terminology

One barrier to the development of a thorough understanding of the effects of pregnancy loss is a lack of agreement among researchers regarding the terminology used to describe the phenomenon. The operational definitions of common terms such as miscarriage, stillbirth, and fetal loss vary widely (see Table 1). Distinctions among the

terms are largely delineated artificially by gestational age rather than by the words of bereaved women. For example, Hutti (1986) defined early pregnancy loss as occurring prior to 16 weeks' gestation, while the American College of Obstetricians and Gynecologists (2007) defined the same term as a loss occurring before 20 weeks. Without a common language, perinatal grief researchers have difficulty comparing studies that include losses at varying gestational ages. Inconsistent use of terminology also hampers literature searches because terms may be used in various ways to describe the same phenomenon. For health care providers, the idiosyncratic use of terms is a barrier to understanding the experience of pregnancy loss.

Table 1. Definitions of Terms Used in Studies of Pregnancy and Infant Loss

Term	Definition
Fetal death ^a	Death before the complete expulsion or extraction from its mother of a product of conception, irrespective of the duration of pregnancy. A death that occurs at 20 or more weeks of gestation constitutes a fetal death. After 28 weeks, it is considered a late fetal death or stillbirth.
Spontaneous abortion ^a	Termination of pregnancy by expulsion of Embryo prior to 22 weeks of pregnancy or below 500 gr. of weight.

Table 1 (continued)

Term	Definition
Stillbirth ^{a,b}	Birth of a baby showing no signs of life. The death of a baby before delivery.
Perinatal loss ^c	Perinatal death defined as the death of the infant within the first week after birth.
Spontaneous abortion ^d	First trimester pregnancy loss. Loss of pregnancy in the first or second trimester.
Early miscarriage ^e	Loss of a pregnancy prior to 16 weeks gestation.
Miscarriage ^f	Unintentional loss of pregnancy prior to the “third month of gestation”.
Early pregnancy loss ^g	The loss of a pregnancy before 20 weeks.

Note. ^a World Health Organization. ^b U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (2009). ^c Toedter, Lasker, and Alhadeff (1988). ^d Friedman and Gath (1989). ^e Murphy (1998). ^f Shapiro (1988). ^g American College of Obstetricians and Gynecologists (2007).

Evidence

Another factor that hinders health care providers’ ability to understand and respond appropriately to pregnancy loss is a lack of consistent evidence. For example, the length of time for which women might be affected emotionally by pregnancy loss has not

been studied. Friedman and Gath (1989), using the Montgomery-Åsberg depression rating scale and the Beck Depression Inventory, found that depressive symptoms following pregnancy loss decreased only 4 weeks post loss. Other researchers (Toedter et al., 2001) noted that perinatal grief ended 2 years post loss, as reflected in an analysis of Perinatal Grief Scale (PGS) scores obtained over a period of 10 years. In most of the studies used by Toedter et al. (2001) to draw their conclusion, participants were recruited at the 6-week post loss office visit, a time at which Friedman and Gath had concluded women would have moved beyond some of the initial emotional distress of pregnancy loss.

Qualitative research by Dyson and While (1998) revealed that perinatally bereaved women continued to experience lingering yearning and sadness even 14 years later. Based on these findings, Dyson and While concluded that the sadness and yearning might never cease, regardless of the passing of time. The new insight they offered challenges health care providers to reconsider the long-term effects of loss.

Conclusive evidence regarding the effect of maternal age on perinatal grief is lacking. Some researchers (Janssen, Cuisnier, de Graauw, & Hoogduin, 1997; Swanson, 2000; Toedter et al., 1988) postulated that as childbearing years passed, mothers would become more acutely aware of the unlikelihood of future pregnancies, which would intensify perinatal grief. Research by Janssen et al. (1997) using the PGS supported this hypothesis but other research using the PGS indicated that increased maternal age did not intensify perinatal grief (Toedter et al., 1988). Using numerous instruments, including the Folkman and Lazarus Revised Ways of Coping Inventory, the Swanson Impact of

Miscarriage scale, Brandt and Weinert's Personal Resource Questionnaire, and the Caring Professional Scale. Swanson (2000) found that maternal age did not significantly affect the personal impact of the loss.

Another area of inconsistency in perinatal loss literature is the role that previous or subsequent births play in the bereavement process. Toedter et al. (1988) and Friedman and Gath (1989) noted that previous live birth ameliorated perinatal grief. In contrast, Janssen et al. (1997) found that the presence of living children intensified perinatal grief; the researchers speculated that the mothers' grief may have been compounded by the loss of an expected sibling for their living children. More recently, Swanson, Connor, Jolley, Pettinato, and Wang (2007) found that perinatal grief was not influenced by having other children.

The contradictory findings on the effects of time, maternal age, and previous live birth could be attributable, in part, to differing inclusion criteria. Specifically, limiting time since loss, as Friedman and Gath (1989) and Toedter et al. (1988) did, allowed these researchers to draw conclusions about the experiences of women from 4 weeks to 2 years post loss only. When time since loss was not limited, as in Dyson and While's (1988) study, new insights into the experiences of bereaved women emerged. Another problem is the use of general mental health instruments, such as in Friedman and Gath's and Swanson's (2000) studies of grief. Instruments that measure general health behaviors do not measure the bereavement process directly; only bereavement-specific instruments provide insight into the actual experience of loss (Niemeier & Burnett, 2001; Niemeier & Hogan, 2001). Many of the secondary effects such as depressive symptoms (Friedman &

Gath, 1989) or personal significance of loss (Swanson, 2000) have been studied but primary outcomes of perinatal bereavement have been neglected. In fact, surprisingly little evidence exists on maternal bereavement following pregnancy loss, and this dearth of information hinders healthcare professionals' ability to understand women's responses to loss and to react appropriately.

Although the literature is replete with recommended interventions, the effects of those interventions have not been studied. Lasker and Toedter (1994) studied parents' satisfaction with post-perinatal loss interventions using a 5-point Likert scale that ranged from 'very satisfied' to 'dissatisfied.' The results indicated that parents were most dissatisfied when they felt that the nursing staff was inattentive to their needs, or insensitive about their loss. Kavanaugh and Moro (2006) offered concrete practice recommendations for nurses, suggesting that they familiarize themselves with grief theories, avoid jargon when discussing perinatal losses, make mementos such as footprints or handprints for bereaved parents, and conduct follow-up phone calls following discharge. Their recommendations were based on their previous research, but the short and long term effects of such interventions have not been tested. In fact, Stratton and Lloyd (2008) recently reviewed recommended hospital-based practice interventions for perinatal loss, including some of those highlighted by Kavanaugh and Moro, and found that surprisingly little evidence exists for many of the recommendations. They concluded that "methodologically rigorous trials are needed to assess. . .outcomes in terms of grief, emotional adjustment, and satisfaction with care" (p. 10).

In addition to the lack of conclusive evidence, misconceptions regarding pregnancy loss may be attributable to the continued application of outdated, rationally constructed theories of maternal attachment that do not articulate with a mother's actual experiences of pregnancy loss. This mismatch between theory and evidence is the focus of the following section.

Disparities

Theory versus Evidence

According to Bowlby (1969, 1973), emotional attachment is a prerequisite for all grief responses. Bowlby's attachment theory is predicated on living persons having reciprocal and long-standing attachment bonds, but Bowlby did not discuss prenatal maternal attachment. Kennell, Slyter, and Klaus (1970) theorized that maternal attachment began some time during pregnancy but they stopped short of elucidating the inner workings of the process. Rubin (1984) put forth a stage-model of maternal attachment and hypothesized that maternal bonding began with quickening at around 20 weeks' gestation, when the mother first perceived the fetus's movement. If Rubin's theory was accurate, women would not be expected to grieve following losses that occurred prior to 20 weeks' gestation. However, research has not supported the notion that 20-weeks gestation is the line between grief and non-grief following pregnancy loss.

Numerous researchers (Abboud & Liamputtong, 2005; Adolfsson, Larsson, Wijma, & Bertero, 2004; Clower, 2003; Friedman & Gath, 1989; Hutti, 1986, 1992; Kolker & Burke, 1993; Van & Meleis, 2003; Wheeler & Austin, 2001) have described profound emotional responses to early pregnancy loss, such as depression and attempted

suicide (Friedman & Gath, 1989). For example, Hutti (1998) noted women's perceptions of the "realness of the pregnancy and the baby within (p. 548)" and not gestational age contributed to their grief responses after early pregnancy loss. Likewise, Kolker and Burke (1993) found that gestational age did not notably affect grief reactions following the loss of a wanted pregnancy.

In light of these findings, it is evident that either Bowlby's (1969, 1973) attachment theory does not apply to perinatal loss or that the theories of maternal perinatal attachment (Kennell, Slyter, & Klaus, 1970) do not provide an accurate description of the process. The theories of maternal attachment may be simply outdated, as these do not account for the effects of advanced technology, such as ultrasound, which allows parents to view their baby, know his or her gender, and see the baby move, and these may foster earlier emotional attachment (Black, 1992; Righetti, Dell'Avanzo, Grigio, & Nicolini, 2005; Robinson, Baker, & Nackerud, 1999). A new, comprehensive theory is needed to explicate the entire process of maternal perinatal bereavement. Brier (2004) proposed that grief following pregnancy loss is similar in course and intensity to the grief that follows other major losses, but conceded that the "essential characteristics of grief following miscarriage are not known" (p. 453). This conclusion may be partially based on the understanding that maternal attachment during pregnancy is not well understood. A new theory of maternal perinatal bereavement that accounts for the process of maternal attachment as it is experienced by women must be derived empirically because, as Davis, Stewart, and Harmon (1988) pointed out, misperceptions about pregnancy loss contribute to the delivery of ineffective nursing care.

Recommendations for nursing care following pregnancy loss abound in the literature. But, according to recent research findings (Abboud & Liamputtong, 2005; Morrissey, 2007), women's accounts of the care they receive at the time of loss do not reflect effective treatment. This mismatch between evidence and clinical practice will be reviewed in the following section.

Evidence versus Practice

Several grounded theory studies (Malacrida, 1997; Säflund, Sjögren, & Wredling, 2004) highlighted the importance of appropriate interventions for perinatal loss, including truthful information delivered in a compassionate manner (Malacrida, 1997) that is "kind but firm. . ." (Säflund et al., 2004 p. 134); an explanation of the cause of death, if possible; reassurance that the mother was not to blame; and information about the likely physical and emotional sequelae of the loss (Malacrida, 1997; Säflund et al., 2004). However, Brier (2004) noted that the emotional sequelae of perinatal loss have not been empirically identified, so patient education in this area is primarily dependent on the application of grief theories that were not specifically developed for perinatal grief.

Nonetheless, a thorough understanding of the process of maternal perinatal bereavement is vital to the development of effective support interventions. The importance of interventions provided at the time of loss cannot be underestimated because research has shown mothers remembered the words and affect of their caregivers even 6 years after the loss (Säflund et al., 2004). A lack of caregiver support or caring following perinatal loss is still cited as a distressing factor for bereaved parents (Abboud & Liamputtong, 2005; Morrissey, 2007).

Qualitative researchers (Adolfsson et al., 2004) revealed that mothers felt abandoned by health care providers who minimized or ignored their reports of the physical symptoms of pregnancy loss. Likewise, long periods of waiting in emergency departments caused mothers to feel increased anxiety and emotional distress (Abboud & Liamputtong, 2005). Mothers noted that health care professionals were noticeably uncomfortable with their emotional displays of suffering after loss (Abboud & Liamputtong, 2005; Maker & Ogden, 2003; Säflund et al., 2004), which might partially explain why some professionals distance themselves from grieving mothers (Morrissey, 2007).

Grieving mothers reported a need for direction from health care providers regarding what to expect during or after treatment (Abboud & Liamputtong, 2005) and what to do with the baby (Säflund et al., 2004). One mother stated, “They didn’t explain everything that they were doing and what we can expect. It was all a surprise for us” (Abboud & Liamputtong, 2005, p. 13). When women did receive information, the manner in which it was delivered was sometimes insensitive; as one mother described, “A physician told us that the child was dead and that I should go home. The message was given in a very inappropriate manner. I became hysterical and almost lost my mind” (Säflund et al., 2004, p. 125).

In addition to a lack of emotional support and direction, mothers are vulnerable to mistreatment during miscarriage. One mother, who felt physically violated by medical students while she was losing her child, stated “To have six doctors in a row come and give you a medical examination, I thought that was really, really bad. It shouldn’t be

happening” (Abboud & Liamputtong, 2005, p. 12). Like these mothers, thousands of women continue to receive substandard care following pregnancy loss. The lack of articulation between evidence and practice has not been studied. Absence of a comprehensive theory of maternal perinatal bereavement leaves health care providers unable to provide useful and accurate information on the sequelae of pregnancy loss, leaving bereaved mothers to question their own reactions to the loss. Several other notable gaps are evident in the perinatal literature, and will be discussed in the following section.

Gaps in the Perinatal Grief Literature

Pregnancy loss is a multidimensional experience which is not fully understood, despite several decades of research. The effect of pregnancy loss on women’s relationships with others, including friends and family members (Callister, 2006; de Montigny, Beaudet, & Dumas, 1999; Van & Meleis, 2003), and spouses (Caelli, Downie, & Letendre, 2002; Hutti, 1992; Murphy, 1998) has been studied. One particular aspect of pregnancy loss that has been overlooked is the effect it has on a mother’s relationship with her living children. Whether bereaved mothers who have been found to experience depressive symptoms post loss (Janssen, Cuisinier, Hoogduin, & de Graauw, 1996) are at risk for neglecting or abusing their living children or alternately drawing closer to them is not known.

Another area that deserves attention is the social and economic cost of perinatal grief in terms of lost work days for the mother and treatment of her depressive symptoms. Clinical care following pregnancy loss is routinely covered by health insurance policies

but emotional care is commonly not covered. Psychological services, such as counseling, may be needed to provide bereaved mothers with emotional guidance and support, and help to ease the transition back to the workplace post loss.

Armstrong (2002) has revealed that mothers experience high levels of anxiety during subsequent pregnancies. Although the extent to which the growing fetus could be affected by that anxiety has not been thoroughly studied, related research suggests a link between stress and preterm birth (Behrman & Butler, 2006; Latendresse, 2009).

Knowledge about the effects of maternal anxiety during pregnancy could help fuel efforts to develop relaxation and stress-management programs for women who experience pregnancy after loss. Although addressing each of the gaps is important, the proper treatment of bereaved mothers is dependent on a comprehensive understanding of the process of maternal bereavement following pregnancy loss.

The pregnancy loss bereavement process is a psychosocial phenomenon that has a distinct beginning, but, the degree to which the process remains as an ongoing reality for bereaved mothers is uncharted. As Uren and Wastell (2002) noted, “the absence of normative information about the possible long-term psychological sequelae of perinatal bereavement only serves to perpetuate simplistic assumptions regarding the recovery process (p. 305).” To address this gap, research aimed at explicating the process that women go through after the loss of a pregnancy is urgently needed to form a basis for effective interventions. The generation of an empirically derived theory of maternal perinatal bereavement would be an important first step for understanding women’s responses to pregnancy loss and would help guide future studies.

Purpose of the Study

The purpose of the study was to generate a substantive theory of maternal perinatal bereavement using the grounded theory method. It is expected such a theory will be useful in educating student nurses and practicing nurses about perinatal bereavement, in hospital policy reform, and in public education in support of women who experience pregnancy loss. Data from the study could be used to develop an instrument that represents mothers' experiences with perinatal bereavement in its empirically based multidimensionality.

Definition of Terms

The following terms were defined for purposes of this study:

Pregnancy loss. Unexpected loss of a pregnancy at any stage of gestation.

Maternal attachment. A general term used to describe the emotional bond between a woman and her child, including an expected (in utero) child.

Perinatal bereavement. The process that occurs following the death of a child.

Bereavement process. The series of events that unfold and encompass the characteristics, intensity, and duration of grief.

Summary

This chapter provided an overview of gaps in the pregnancy loss literature. A case was made for the need to generate an empirically derived theory of the maternal bereavement process following pregnancy loss. Research documented since the 1980's regarding pregnancy loss consists of fragmented and conflicting findings, inconsistent terminology, disparities between practice and evidence, and rationally developed theories

of maternal attachment that are not consistent with evidence accumulated to date.

Existing theories of perinatal bereavement are based on speculation of what mothers experience at the time of loss rather than on mothers' description of the loss. A grounded theory, derived from the words of perinatally bereaved women is needed to provide a comprehensive understanding of their losses, and will provide a platform for health care interventions that fit the experiences of bereaved mothers.

CHAPTER TWO:

REVIEW OF LITERATURE

This chapter provides a review of literature concerning women's responses to pregnancy loss. Electronic database searches were conducted using the key terms miscarriage, pregnancy loss, bereavement, perinatal loss, maternal grief, fetal loss, perinatal grief, perinatal bereavement, and fetal death. Factors that were found to influence maternal responses to pregnancy loss, such as reproductive history, culture, gestational age, and the responses of others are also reviewed. Because the focus of the study was specifically on pregnancy loss, studies on maternal reactions to the loss of a live infant who later died were excluded. The chapter concludes with a summary of research findings and a discussion of how the gaps in the extant research support the need for the study.

Women's Responses to Pregnancy Loss

Research regarding women's experiences of pregnancy loss has been growing for over three decades. Qualitative studies have been conducted to explore women's responses to loss. Factors that influence maternal responses to loss have been studied quantitatively. Hutti (1986) conducted a qualitative, exploratory study of early pregnancy loss, framed by Dougherty's cognitive model. Hutti explained that Dougherty's cognitive model indicates that individuals who experience similar events will have similar experiences, but variations occur due to "individual predilections and

cultural code” (p. 379). Using nondirective, open-ended questions, Hutti (1986) collected data during two interviews with two women who had, between them, experienced a total of three miscarriages. Data were analyzed according to the procedure developed by Dougherty and revealed that mothers recognized and assessed the pregnancy, noting signs of progression, as well as “bad signs” (Hutti, 1986). The women also differentiated between recognition of miscarriage as a possible event and miscarriage as an actual event, which were viewed as two distinct processes.

In a subsequent study of early pregnancy loss, also framed by Dougherty’s model, Hutti (1992) interviewed six married couples (12 participants), who had lost an expected child through miscarriage (< 16 weeks) during the previous 18 months. The seven stages of events described by the parents were recognition and assessment of the pregnancy, recognition that “something is wrong,” recognition of miscarriage as an actual event, medical intervention, returning home/aftermath, trying again, and subsequent pregnancy. The inclusion of both parents revealed differences in the accounts of fathers and mothers that Hutti attributed to perceptions of the realness of the pregnancy and attachment to the expected baby. Fathers often noted that the pregnancy “did not seem real to them (p. 409)” because they did not experience the same changes as their partners did. Although Hutti described the milestones that women reached following pregnancy loss, the psychosocial process that occurred at each point was not fully explicated. In a later phenomenological study with women who experienced early miscarriage (prior to 16 weeks’ gestation) Harvey, Moyle, and Creedy (2001) reported themes similar to those offered by Hutti (1986, 1992).

In their phenomenological study of early pregnancy loss, Harvey et al. (2001) interviewed three participants who had experienced pregnancy loss within the previous 12 months. The researchers extracted the essences: loss of motherhood, uncertainty about future pregnancy, guilt, clinical care, and need for emotional support. As in Hutti's (1986, 1992) research, the mothers noted the actual loss, spoke about the care they received at the time of loss, and expressed their concerns regarding future pregnancies. Additionally, the mothers spoke of guilt and a need for emotional support which was consistent with other perinatal loss research (Adolfsson et al., 2004; Dyson & While, 1998; Friedman & Gath, 1989; Harvey et al., 2001; Hsu, Tseng, Banks, & Kuo, 2004).

In a phenomenological study involving 13 women who had experienced miscarriage, Adolfsson et al. (2004) identified the essences of guilt and emptiness, feeling emotionally split, bodily sensations, loss, grief, and abandonment. The findings from this study were consistent with the results of previous qualitative research on pregnancy loss (Harvey et al., 2001; Hutti, 1986, 1992) but also offered a new insight: the notion that mothers often felt emotionally abandoned after early pregnancy loss, highlighting the need for research on social support after loss.

A Straussian grounded theory study of 20 African American women who had experienced miscarriage during the previous 3 years (Van & Meleis, 2003) revealed that women coped with personal reactions and responses after involuntary pregnancy loss, reactions of others, memories of the baby, and subsequent pregnancies. In addition to pointing to a need for support and commenting that the responses of others could cause emotional distress, the importance of religion and spirituality were identified. The authors

stated that this finding denoted a greater reliance on spirituality for strength among African American women than among European American women. It should be noted that the participants were recruited from, among other places, church activities, which may have influenced this finding.

Van and Meleis (2003) asserted that responses to pregnancy loss among African American women are influenced by, among other factors, “religious and cultural values and beliefs” (p. 29). Because the proportion of pregnancy losses is nearly equivalent across races (Goldhaber & Fireman, 1991; Goldhaber, Fireman, Saraiya, & Berg, 2000; Saraiya et al., 1999), the role that misunderstandings regarding cultural norms and customs about death and dying (Hsu et al., 2004; Van & Meleis, 2003) have in influencing women’s responses to loss and their perceptions of support is particularly important. Van and Meleis’s (2003) finding that the women needed to cope with the insensitive responses of others in addition to their own reactions to pregnancy loss was consistent with the results of studies that included primarily Caucasian women (Adolfsson et al., 2004; Dyson & While, 1998; Harvey et al., 2001; Hutti, 1986, 1992). Coping with memories of the baby was a finding that had not been reported in other studies of pregnancy loss and represents a part of the bereavement process that was previously unknown.

Van and Meleis’ (2003) study is important because it describes the experiences of women who had experienced miscarriage, an understudied population, and African American women, who are especially underrepresented in the literature. Other researchers illuminated cultural influences on perinatal grief among Taiwanese women.

In an ethnographic study of late pregnancy loss (> 20 weeks), Hsu et al. (2004) sought to determine how women interpreted the deaths of their babies within Taiwanese culture, one in which talking about death is taboo and unborn children are not recognized. Asian women are not expected to express their grief openly and tend to somaticize their suffering (Hsu et al., 2004). The finding that cultural expectations influence grief responses is consistent with Wheeler and Austin's (2001) findings that pregnancy loss can result in physical symptoms of grief among American teens whose emotional suffering is counter to cultural expectations. After conducting 20 interviews, Hsu et al. reported four major themes: loss of control, broken dream, shattered self, and something wrong with me. Hsu et al. reported that the mothers experienced feelings of guilt and blame, despite believing that they had done nothing to cause the deaths of their babies.

Self-blame was also noted in a qualitative descriptive, exploratory study of three women who had experienced neonatal and late fetal loss (St. John, Cooke, & Goopy, 2006), that resulted in three themes: (a) dealing with the experience of grief, loss, anger, and self-blame in a world of silence; (b) being on the outside looking in; and (c) being changed or transformed by loss. The themes reported by St. John et al. (2006) were consistent with the findings of Hsu et al. (2004) on late pregnancy loss.

Another descriptive qualitative study (Dyson & While, 1998) of eight women who had experienced late pregnancy losses (24-40 weeks) offered findings consistent with previous research (Harvey et al., 2001; Hutti, 1992; Hutti, dePacheco, & Smith, 1998), as well as new insights. The themes reported were (a) diagnosis, (b) lack of knowledge about stillbirth, (c) labor, (d) saying goodbye to the baby, (e) helpful and

unhelpful things, and (f) subsequent pregnancy. Dyson and While (1998) noted that even 14 years post loss, women still felt the pain of the loss of their babies, which is also consistent with the subprocess of coping with memories of the baby, identified by Van and Meleis (2003), who suggested that the bereavement process may be lifelong.

Questions remain regarding the effect of time on perinatal grief. Some (Friedman & Gath, 1989) have suggested that emotional recovery may begin as early as four weeks post-loss. Others (Hutti et al., 1998; Janssen et al., 1996; Janssen et al., 1997; Toedter et al., 1988) indicated that grief after pregnancy loss decreases during the subsequent 18 months to 2 years but, as Dyson and While (1998) noted, the painful memories of pregnancy loss may last a lifetime.

The qualitative research reviewed to this point offered only partial insights into how the maternal bereavement process unfolds. The existing evidence indicates that maternal bereavement involves feelings of guilt and self-blame (Adolfsson et al., 2004; Harvey et al., 2001; St. John et al., 2006), anger (St. John et al., 2006), detachment (Hsu et al., 2004), and a need for emotional support (Hutti, 1992; Hutti et al., 1998; Van & Meleis, 2003). Questions still remain regarding the role of religion in the bereavement process, the effect of one's cultural heritage on grief responses and perceptions of support, and whether the bereavement process ends or exists as a lifelong ongoing reality for bereaved mothers. Several of the factors thought to affect the processes of maternal bereavement have been studied quantitatively, and are reviewed in the following section.

Influences on Maternal Responses to Pregnancy Loss

Maternal responses to pregnancy loss are not wholly understood, but several studies have shed light on factors that influence mothers' reactions to pregnancy loss. In their perinatal loss project, Toedter et al. (1988) sought to determine factors that had the greatest effect on perinatal grief using the Perinatal Grief Scale (PGS). They hypothesized that (a) previous loss would not significantly affect PGS scores; (b) previous live birth would lower PGS scores; (c) gestational age would increase PGS scores; (d) strong marital bonds would decrease PGS scores; (e) social class would not affect PGS scores; (f) poor mental health would increase PGS scores; (g) fertility problems would increase PGS scores, and (h) poor physical health would increase PGS scores (Toedter et al., 1988). Other variables not derived from the literature were predicted to increase PGS scores; these other variables included lack of religiosity and the unlikelihood of subsequent pregnancy (Toedter et al., 1988). To test their hypotheses, Toedter et al. administered the PGS, developed specifically for this study, to a sample of 138 women and 56 men at 6-8 weeks, 1 year, and 2 years post loss.

The results of the study (only maternal responses were reported) indicated that all of the hypothetical relationships predicted were supported, with the exception of increased maternal age, which was not shown to increase perinatal grief (Toedter et al., 1988). Stepwise multiple regression indicated that poor maternal health, increased gestational age, poor marital relationship, and preloss mental health symptoms were the strongest predictors of perinatal grief, as measured by the PGS (Toedter et al., 1988). These results were inconsistent with qualitative reports of mothers' experiences of

perinatal loss in which a link between gestational age and perinatal grief was not established (Adolfsson et al., 2004; Dyson & While, 1998; Hutti, 1992; Swanson et al., 2007). Toedter et al. also reported that women with a history of poor mental health were more vulnerable to the psychological consequences of pregnancy loss. If the women who experienced early pregnancy loss were the same participants who had a history of poor mental health, then this factor, rather than gestational age itself may explain the women's psychological reactions to the loss.

In a study of the psychological impact of spontaneous abortion, Friedman and Gath (1989) used a mixed-method, cross-sectional approach at 4 weeks post loss with 67 women who experienced first ($n = 61$) and second trimester losses ($n = 6$) losses. As in the study by Toedter et al. (1998), the results of Friedman and Gath's (1998) study indicated that the women with a history of mental health issues ($n = 32$) reported more depressive symptoms and more difficulty with social and marital relationships post loss.

Other researchers (Wheeler & Austin, 2001) hypothesized that early pregnancy loss would alter family relationships, lower self-esteem, and cause symptoms of depression among adolescents. These hypotheses were tested using a cross-sectional comparative design with four groups of adolescents: never pregnant ($n = 62$), pregnant ($n = 50$), early pregnancy loss without subsequent pregnancy ($n = 31$), and early pregnancy loss with subsequent pregnancy ($n = 21$). The results of the study indicated that adolescents who experienced pregnancy loss had higher scores on the Children's Depression Inventory and the Loss Response List than did adolescents who were never pregnant, or were pregnant ($p = 0.04$). The Loss Response List is an 83-item scale

developed by Wheeler to measure the physical, emotional, social and cognitive effects of grief. The results of the study indicated that the participants experienced both grief and depressive symptoms after pregnancy loss.

The personal significance of pregnancy loss has been considered a predictor of depressive symptoms following pregnancy loss (Swanson, 2000). Applying Lazarus' theory of emotions and adaptation, Swanson (2000) used path analysis to determine the effects of several variables on 174 participants' responses to pregnancy loss (< 20 weeks). Variables predicted to influence personal significance were increased maternal age, number of previous miscarriages, increased gestational age, provider caring, and number of living children. Family income was predicted to influence both coping mechanisms and depressive symptoms.

The results of Swanson's (2000) study indicated that at 4 months and at 1 year post loss, depressive symptoms were influenced by the personal significance of the loss, lack of social support, lack of financial resources, lack of positive coping strategies and emotional strength, and inability to conceive again within 1 year post loss (Swanson, 2000). Swanson's findings regarding the influence of maternal mental health and ability to conceive again were consistent with other findings (Hutti, 1992; Janssen et al., 1997; Kavanaugh & Hershberger, 2005; Toedter et al., 1988). The importance of social support in decreasing depressive symptoms was also echoed in other studies (Hutti, 1992; Murphy, 1998; Van & Meleis, 2003). In contrast to Toedter et al.'s (1988) findings that social class did not affect perinatal grief, Swanson (2000) found a significant negative

relationship between family income and depressive symptoms, which may be explained by greater ability to pay for professional support services in higher income groups.

Another study (Janssen et al., 1996) of the factors that affected the mental health of 227 women 6, 12, and 18 months post pregnancy loss determined that at 6 months pregnancy loss was associated with depressive symptoms ($p = 0.04$) among the loss group but not among the comparison group ($n = 213$), who had experienced live birth. By 12 and 18 months post loss, the differences between the groups were not statistically significant, indicating that the psychological symptoms experienced post loss appeared to decrease within 1 year.

Another aspect of the study by Janssen et al. (1996) was published in 1997, presenting the results of the administration of the PGS as part of the original research protocol. The researchers had hypothesized that the following factors would increase grief: increased gestational age; preloss neuroses; preloss psychiatric symptoms; poor physical health; absence of living children; history of fertility problems; increased maternal age; poor marital relationship; and poor quality social networks (Janssen et al., 1997). The hypotheses were drawn largely from the work of Toedter et al. (1988). In contrast to Toedter et al., Janssen et al. (1997) found that the factors most predictive of grief intensity were increased gestational age, preloss neurotic personality, preloss mental health symptoms, and the presence of living children. Additionally, in contrast to the findings of Toedter et al., older mothers had higher PGS scores than did younger mothers (Janssen et al., 1997). Time since loss was found to be a mediating factor in perinatal

grief, which is consistent with other findings (Friedman & Gath, 1989; Janssen et al., 1996; Toedter et al., 1988).

Summary

Research on perinatal loss has revealed the importance of understanding the impact of pregnancy loss and factors that might influence women's reactions to the loss. Recently, Briar (2004) reviewed extant grief theories in light of perinatal grief literature, and concluded that the perinatal grief process may mirror other forms of grief more closely than had been heretofore thought. But comparative studies have not been conducted. Because clinicians differentiate normal grieving from dysfunctional grieving based on intensity and length of grief symptoms (Hogan, Worden, & Schmidt, 2004), it is crucial that the symptomatology of normal grief and the interplay among the symptoms be made known.

Findings from qualitative studies have offered insights into the experiences of bereaved mothers, including feelings of guilt and emptiness (Adolfsson et al., 2004); failure (Hutti, 1992); numbness, denial, and anger (Hutti, 1986); and depression (Hutti, 1986). Variations in grief responses were thought to be due to attribution of realness to the pregnancy (Hutti, 1986, 1992; Murphy, 1998), cultural traditions (Hsu et al, 2004; Van & Meleis, 2003), or the responses expected by others (Murphy, 1998). These findings helped lay the groundwork for the development of hypotheses used in subsequent quantitative studies.

Quantitative studies suggested that maternal responses to pregnancy loss were influenced by poor maternal physical and mental health (Friedman & Gath, 1989; Janssen

et al., 1997; Swanson, 2000; Toedter et al., 1988), marital relationships and social support (Swanson, 2000; Toedter et al., 1988), and fertility issues (Janssen et al., 1996; Swanson, 2000). Results indicating that gestational age intensified perinatal grief (Janssen et al., 1997; Toedter et al., 1988) were inconsistent with other findings (Harvey et al., 2001; Hutti, 1986; Kolker & Burke, 1993). Results on the importance of social status were also conflicting (Swanson, 2000; Toedter et al., 1988). The influences of culture and race on maternal bereavement reactions following pregnancy loss is not well understood but may influence women's coping strategies and their interpretations of the responses of others.

Women who experienced pregnancy loss were found to be at greater risk for depression than those who had not suffered a loss (Friedman & Gath, 1989; Janssen et al., 1996; Wheeler & Austin, 2001) and frequently reported feelings of loss, grief, guilt, self-blame, denial, and detachment (Friedman & Gath, 1989; Harvey et al., 2001; Hsu et al., 2004; St. John et al., 2006). Some women reported an aversion to pregnant women and babies following pregnancy loss (Friedman & Gath, 1989). A few women were so affected by pregnancy loss that they attempted suicide (Friedman & Gath, 1989).

Overall, research findings regarding pregnancy loss are conflicted and fragmented. Although some have suggested the process may be similar to other types of losses (Brier, 2004), the psychosocial process mothers experience following pregnancy loss has not been identified systematically. To address this gap, a grounded theory study was conducted to provide much-needed insights into the experience of pregnancy loss.

Grounded theory method is rooted in the precepts of symbolic interactionism and was developed by two sociologists (Glaser & Strauss, 1967) as an approach to empirical

theory discovery. It is an inductive process used to generate theory from the individual level, which could then be generalized and applied to practice. In other words, grounded theory is a means of identifying the basic psychosocial processes involved in major life events such as bereavement. For these reasons, grounded theory method is particularly suitable for the study of pregnancy loss, as the results are expected to be useful for pregnancy loss researchers, nurses and others in clinical practice, and educators who prepare students to work with bereaved mothers.

CHAPTER THREE:

METHODOLOGY

Research Approach

Grounded theory has been identified as an appropriate approach for developing a much needed theory of perinatal bereavement. In this study, classic grounded theory method (Glaser & Strauss, 1967) was chosen because the need for a substantive theory of unexpected pregnancy loss was identified upon review of the perinatal loss literature. Grounded theory method is the method appropriate for the study of life cycle interests (Glaser, 1992), such as unexpected pregnancy loss. According to Benoliel (2001), grounded theory methodology is well-suited for uncovering women's experiences with difficult life circumstances.

Although several studies have identified factors that influence maternal reactions following pregnancy loss, no studies provided a systematically derived description of the basic psychosocial processes women experience following pregnancy loss. Grounded theory method was deemed the most appropriate means for addressing the specific gap identified in the literature. The substantive theory generated from the data gathered during this study was expected to be directly applicable to nursing practice because it will be grounded in the words of the women who have experienced pregnancy loss (Benoliel, 2001; Glaser, 1992).

Setting

Participants were recruited through an independent women's health practice operated by two doctorally prepared nurse practitioners in northeastern Pennsylvania. Most participants resided in the surrounding two-county area, which is populated primarily by White, non-Hispanic residents, with a small population of Blacks (2.9%) and Latinos (4.5%) (U.S. Census Bureau, 2008). The annual median household income is approximately \$42,000 in both counties.

Sample

A purposive sample of 19 participants who experienced unexpected pregnancy loss was included in this study. Sampling continued until saturation of data was reached and no new categories emerged from data. The participants were at least 18 years old, and able to speak and read English.

Recruitment

With the appropriate permissions in place, a call for participants, consisting of an 8 x 10 color table-top display (see Appendix B), was placed on the tables in the waiting areas of the nurse practitioners' offices. The notice informed potential participants that a study was being conducted on unexpected pregnancy loss. Information cards, which stated the purpose of the study and the researcher's contact information, were printed on yellow card stock and placed near the notice (see Appendix B). The nurse practitioners identified women who met the inclusion criteria during office visits when reviewing each client's obstetric history. Potential participants were informed of the study by the nurse practitioner (see Appendix B for the nurse practitioners' script), and given an information

card. Interested participants contacted the researcher by telephone or email, using the contact information provided on the cards.

Protection of Human Subjects

The researcher received approval from the Institutional Review Board for the Protection of Human Subjects of Loyola University Chicago, and the University of Scranton to conduct the study (see Appendix A). Data collection required more than the 1-year period originally approved, and applications were renewed appropriately (see Appendix A). The researcher also received approval from the cooperating clinic to conduct the study (see Appendix A). When a potential participant contacted the researcher, the purpose of the study, data collection method, risks and benefits associated with participation, and confidentiality procedures were explained via telephone conversation. If the potential participant agreed to schedule an interview, her confidentiality was maintained as follows:

1. The only document containing the participant's name was the consent form (see Appendix C). The consent form was coded, and all other documents, such as the transcripts and demographic form, bore only the code number.
2. The completed consent forms were stored in a locked cabinet in the researcher's office.
3. The completed consent forms and demographic forms were stored separately.
4. The completed consent forms and transcripts of the interview were stored separately.

5. Digitally recorded interviews were transcribed by a transcriber who had no knowledge of the identities of the participants, and who agreed to maintain confidentiality of the data. Any identifying information, such as a name or place was transcribed using the designation XXXX. The digital recordings were destroyed after data analysis was completed.

6. Notes or memos written by the researcher excluded the participants' names.

7. Medical records of women who were clients at the practice were not reviewed as part of this study.

At the time of the interview, the consent form was reviewed, which included permission to record and transcribe the interview. The participant was asked to sign two copies of the consent form (see Appendix C); one was retained by the researcher and the other was given to the participant. The researcher's copy of the consent forms will be maintained in a locked cabinet for a period of 5 years. All participants were ensured that they could discontinue participation at any time without consequence. The researcher planned to end the interview and offer information on support options, such as local counseling practices, and perinatal support groups (see Appendix C) if any participant became distressed during the interview, as evidenced by crying and inability to continue the interview, or by verbally expressing her desire to end the interview. Ending the interview prematurely and offering support-related information was not necessary during any of the interviews. All participants were informed that there were minimal risks and no known benefits associated with participation.

Data Collection

Upon receiving written and verbal consent, each interview began with the researcher asking open-ended questions that allowed the participant to tell her story, in her own words, as completely as possible (Hogan, Morse & Tasón, 1996). An interview guide was used for each interview (see Appendix C). Upon completion of the interview, the participant was asked to complete a brief demographic questionnaire (see Appendix C), which was used to develop a description of the sample. Each interview lasted approximately 1 hour. All interviews were digitally recorded and transcribed verbatim. The transcript of each interview was reviewed by the researcher for content and compared with the recording for accuracy. The researcher made corrections as needed.

Data Analysis

Consistent with grounded theory method, data collection and analysis took place simultaneously (Glaser, 1992; Glaser & Strauss, 1967). Memos were written by the researcher to note thoughts or questions about the data as theoretical sensitivity evolved (Glaser, 1978; Glaser & Strauss, 1967). Memos facilitated capture of the researcher's biases, to prevent preconceptions from influencing data analysis. These steps ensured that the data guided subsequent interview questions and helped shape the emerging theory.

Data analysis commenced by analyzing each transcript word for word. Each discrete piece of data was coded. Data that had similar properties were assigned to each specific category. Dissimilar words or phrases represented new categories. Data collection continued until saturation of the categories occurred and no new insights emerged from the interviews (Glaser, 1978, 1992; Glaser & Strauss, 1967). The category

that occurred most frequently, or seemed to be of greatest concern to the participants, was considered the core category, and the other categories were developed around it (Glaser, 1978).

An inductive process of integrating the categories allowed the researcher to limit the scope of the emerging theory by subsuming less abstract categories into more abstract categories and then linking these together conceptually. This collapsing of categories increased the density of the substantive theory. Because the theory was derived from bereaved mothers' descriptions of the events associated with pregnancy loss, internal validity was systematically built into the theory.

Judging a Grounded Theory Study

According to Glaser and Strauss (1967), when a grounded theory is generated using data obtained from those who have lived an experience, the researcher can feel confident "in his bones" (p. 225) that the results are credible. The theory that is developed in the study should meet five criteria, as defined by Glaser and Strauss (1967): (a) to predict and explain behavior, (b) to further advance theory in a field, (c) to be useful in practice, (d) to provide perspective, and (e) to guide future research. The researcher bears the burden of conveying credibility to the reader by supporting each theoretical assertion with data (Glaser, 1978; Glaser & Strauss, 1967). The reader must be provided with enough supportive evidence to easily make the connections among the theoretical suppositions.

Readers with experience in the area of study are expected to judge the applicability of the substantive theory in various structures or settings.

[I]t is important to note that when a theory is deemed inapplicable to a social world or social structure, then it cannot be invalid for that situation. . . .The invalidation or adjustment of a theory is only legitimate for those social worlds or structures to which it is applicable. (Glaser & Strauss, 1967, p. 232)

This statement indicates that the researcher must delimit clearly the boundaries of the theory, determine which situations the theory is or is not applicable, and support each assertion with data.

Summary

In this chapter, justification was made for use of grounded theory research study, the aim of which was to develop a substantive theory about pregnancy loss. The research protocol was presented, and methods to ensure credibility and scientific merit of the research were reviewed. The study resulted in a substantive theory which provides a deeper understanding of maternal perinatal bereavement. This new understanding is expected to be useful to health care providers devising empirically grounded clinical interventions for bereaved mothers.

CHAPTER FOUR:

RESULTS

The purpose of this chapter is to present the results of a classic grounded theory study of maternal perinatal bereavement. Data were gathered from one-to-one interviews with women who had experienced pregnancy loss and were analyzed using classic grounded theory method. The core category (Glaser, 1978), which subsumes the majority of the categorical data and explains how the women worked through their main concern, was identified, as were five key categories and their subcategories that constitute the theory. Throughout the text, the first word of a category is capitalized, and subcategories are *italicized*. Data revealed that the categories and subcategories were arranged in temporal order.

The participants generally referred to themselves as mothers and thus, throughout this chapter, the words “participant” and “mother” will be used interchangeably. Regardless of the age of gestation when the death occurred, the mothers referred to losing a “baby.” The mother’s language referring to the loss is used in this chapter.

The grief described by the mothers was initially overwhelming and all-consuming to them. In time, and by taking intentional steps to move beyond the pain, the women noted that the pain eventually decreased in intensity and became episodic. The nature of the pain of perinatal loss changed from an intense, gnawing pain to episodic periods of regrieving characterized by longing and yearning for the lost child.

Several mothers noted the re-emergence of grief on the anniversary of the loss, the baby's due date, and during holidays. The absence of the child was felt on special or symbolic days, such as the start of the school year and when a subsequent child was born. Notably, some of the mothers became emotional, and cried during the interview when recalling the circumstances of the loss, regardless of the amount of time that had passed since the loss.

Sample

Nineteen participants who were at least 18 years of age, able to read and speak English, and who had experienced at least one pregnancy loss were recruited from a nurse practitioner-operated women's health clinic in northeastern Pennsylvania or through participants referring other women who had experienced pregnancy loss. Demographic information was analyzed using SPSS version 16.0. The participants were between the ages of 19 and 43 years (mean = 30.8 years). The number of pregnancy losses each participant experienced ranged from one to seven, with most (68%) having experienced a single loss. Two of the participants lost one full-term twin; the remaining 17 participants experienced the death of a singleton. The majority (74%) of the participants had living children at the time of at least one loss, and 52 % subsequently experienced a live birth.

In total, the participants experienced a total of 33 pregnancy losses. Of those 33 losses, 52% ($n = 17$) took place during the first trimester (conception to 12 weeks gestation), 33% ($n = 11$) occurred during the second trimester (up to 28 weeks gestation),

and 15% ($n = 5$) occurred during the third trimester (greater than 28 weeks gestation).

The time since loss ranged from 12 weeks to 28 years (mean = 8.1 years).

Nearly all of the participants (90%) were married at the time of their first loss, and were still married at the time of the interview. Most of the participants (95%) were White, and 5% were Black, which is representative of persons living in the area in which the study was conducted. Seventy-four percent of the participants were Christian, 10% were Jewish, and 16% reported no religious affiliation. Household income for the sample ranged from \$21,000 to greater than \$60,000.

Recruitment

Participants were recruited through a women's health clinic in northeastern Pennsylvania and through participant referrals. When a potential participant contacted the researcher, the purpose of the study, data collection method, risks and benefits associated with participation, and confidentiality procedures were explained via telephone conversation. If the potential participant agreed to be interviewed, and individual face-to-face interview was arranged at a time and place convenient for the participant.

Data Collection and Analysis

Interviews were conducted at the participant's home, the participant's workplace or in the researcher's office, for the convenience of the participant. One interview was conducted by telephone at the participant's request. Prior to beginning the interview, the consent process was discussed, and the consent form was reviewed and signed. Each participant received a copy of the consent form, and a list of pregnancy loss resources was offered. An interview guide was used, and each participant was encouraged to tell

her story in its entirety. Each interview lasted approximately 1 hour and was digitally recorded after the participant's permission to do so was obtained. The recording was then transcribed verbatim by a transcriptionist and reviewed word for word for accuracy by the researcher.

The first interviews were conducted with women whose losses had occurred many years earlier for the most part, but they nevertheless indicated that they continued to miss and long for their deceased child. Women were subsequently recruited who had experienced losses within the previous 5 years in order to obtain more recent descriptions of loss and to capture any nuanced data that might have been lost by the passage of time, as may have been the case with the initial set of participants. An interview guide was used during each interview (see Appendix C), but questions were modified during the data collection process to explore emerging theoretical categories.

Consistent with grounded theory method (Glaser & Strauss, 1967), data collection and analysis proceeded simultaneously. Data analysis began by using open coding procedures. Analysis involved reading each transcript and identifying each word or phrase that represented a discrete datum. Similar words or phrases were grouped together by common properties of meaning and these sets of data were assigned codes. The codes assigned to each set of data were taken directly from the words of the participants. Data collection continued until no new substantive content emerged from the data. This process of open coding resulted in 335 codes.

Data with similar properties were assigned to the same theoretical category. Categories were then further subsumed under higher level categories. For example, early

in the data analysis process, the categories “sad” and “disappointed” were grouped together as properties of the category “emotional distress.” As the researcher asked questions about the data, its meaning, and how the incidents represented categories or properties of categories, memos were written. Memos to capture the researcher’s theoretical thinking about the data, to document questions that arose from data analysis and to capture the biases the analyst had toward the data. Creating these memos helped the researcher to group the data together inductively to form categories and determine their properties and to remain as objective as possible.

The process of grouping similar data continued until five key categories and their 19 properties had been established. For example, a participant described “bearing the burden” of her loss, stating, “I just felt like the burden was constantly on me.” An inductive process was used to determine that codes like “emotional distress” and “financial uncertainty” represented similar aspects of the process of maternal perinatal bereavement and could be subsumed under the category of “bearing the burden.” Unique categorical data that added explanatory power were subsumed as subcategories under higher level categories. For example, the category of “bearing the burden” included the property of “emotional distress,” which included the codes of “sad” and “disappointed,” but another property of this category was “financial uncertainty,” which included the codes of “bills” and “sick leave.”

Although “emotional distress” and “financial uncertainty” were both considered burdens related to perinatal loss, they were not similar enough to denote a single property of the category “bearing the burden,” without raising the level of abstraction. In this

instance, the researcher conceptualized both of these dimensions of “bearing the burden” as the property *apprehending the loss*, which denoted the mothers’ attempts to place the various aspects of the loss within the context of their lives. This inductive approach to the data helped to clarify emerging concepts and to create a parsimonious substantive theory.

Throughout the research process, theoretical sensitivity (Glaser, 1978), which is the ability to notice new theoretical ideas, developed. Each new theoretical idea had to earn its right to be included in the emerging theory (Glaser, 1998). To ensure that the categories that emerged from the data were representative of the experience of maternal perinatal bereavement, the researcher conducted theoretical sampling (Glaser & Strauss, 1967), which involved exploring some aspects of the developing theory with subsequent participants, and verifying others.

Theoretical sampling (Glaser & Strauss, 1967) did not have to be undertaken with each new concept that was discovered in the data. When a concept that had “grab” (Glaser, 2002, p. 3) was mentioned by a participant, the researcher explored the experience to determine if it was truly representative of the experience of maternal perinatal bereavement. Theoretical sampling increased the richness of the data and allowed the researcher to answer the questions that arose from the constant comparison process (Glaser, 2002). For example, toward the end of the interviews, the association between missing and longing for the child, regardless of the time that had passed since the death became clear. Individual mothers also spoke of the child as a continuing presence in their lives, but it was not clear whether this experience could be generalized. Because the researcher became sensitive to this association, mothers were asked about

this at the end of interviews and previous interviewees were contacted to confirm this experience.

To verify that an experience was truly part of the bereavement process, the researcher reviewed all of the transcripts looking for evidence of missing or longing and re-contacted five women who had been interviewed prior to the identification of the concept to explore further this new discovery. Once it was determined that sufficient evidence existed to support its inclusion, the concept was incorporated into the substantive theory. When sufficient evidence existed to empirically support all of the categories, and no new concepts were determined to be emerging from the data, saturation was deemed to have occurred. Axial coding procedures were then used to integrate findings and to identify the sequencing of categories and subcategories. The categories were then conceptually linked together, forming the empirically derived substantive theory of maternal perinatal bereavement.

Findings

The primarily temporal nature of the theory categories and subcategories was described in Data Collection and Analysis. It was determined that because the categories and subcategories had a beginning, middle, and end point, the theory would be operationalized as a stage theory. Stage theories, in contrast to phase models, “posit discrete transitions from one kind of behavior and form of existence to another” (Williams, 2003, p. 273). The substantive theory discovered in this study included five stages: Experiencing the Pregnancy, Losing the Baby, Bearing the Burden, Working through the Pain, and Transcending the suffering (see Figure 1).

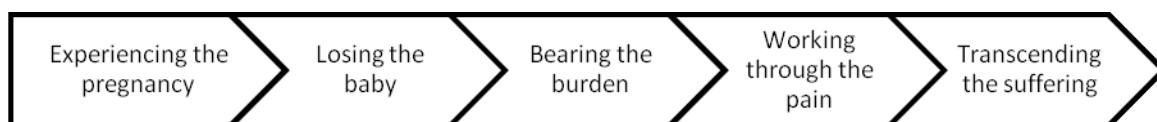


Figure 1. Five stages of the substantive theory.

Participants moved through each of the stages of the substantive theory without returning to earlier stages. Each stage of the substantive theory involved subprocesses that were the subcategories identified during data analysis (see Table 2). The length of time it took participants to move through the stages varied. Unlike most stage theories in which growth ends upon completion of the last stage, data used to generate this substantive theory showed that the bereavement process does not end. Instead, it is an ongoing process that continues to have an impact on the lives of the women who experienced the death of an expected baby.

In general, those who experienced early pregnancy loss moved through the first four stages in approximately 3-6 months post loss. For example, after a loss at 8 weeks' gestation, a participant recalled "having more good days than bad" approximately 3 months post loss. Likewise, a mother who experienced a loss at 13 weeks' gestation stated, "It's gotten a little better lately," (4 months post loss). After a loss at 11 weeks' gestation, another mother noted, "It was almost a half year, I think, before I really felt like I could engage again completely." A mother who experienced a loss at 12 weeks' gestation noted, "I think it took a good 6 months to feel like myself again."

Those who experienced pregnancy losses after the 16th week of gestation described more intense grief that lasted 9-12 months and was more difficult to transcend. A participant who experienced a full-term loss stated, “I would say that it had to be over a year,” before she started to feel better, and another said, “When I gradually got [better], I think it started happening the first year.” A mother who lost a full-term twin recalled, “I can’t even pinpoint it and say, ‘Wow, yeah, this is when my eyes opened,’ but I know that I was messed up until the first year. . . the whole first year was horrible.” Nine months after a full-term loss, another mother explained, “I don’t wake up crying, I . . . wake up and that, that’s not necessarily the first thing I think of. . .”

Once the women were able to work through the initial pain of the loss, they began the final stage, Transcending the suffering, which is the onset of a permanent, but changed, new ongoing reality. Each stage and its subprocesses are described in the following sections.

Core Category

In a classic grounded theory study, the researcher is charged with discovering the main concern of the participants and determining how it was resolved. (Glaser, 1998). In this study, the women faced the pain of bereavement through “pushing on.” Pushing on was an active process in which the women willed themselves to move beyond the suffering. The women described the process of pushing on with statements such as, “I’m just trying to let go a little bit of the coping stuff, the escapes I’ve been using and just kinda get back into. . . taking care of myself,” and another stated, “I’m trying, I’m getting better, but for a while there I was not. . .” Similarly, another explained, “I pushed myself

not to grieve, pushed myself, pushed myself, to um, to work hard and push through things. . .”

Because the process of Pushing On explains how the women coped with the loss, and repeatedly faced periods of regrieving, it is the core category. Pushing on explains how the women found the emotional strength to move beyond the pain of the loss, and to eventually find meaning in their pain. The category of pushing on is evident throughout the course of maternal perinatal bereavement. The mothers described pushing on when faced with signs of loss or with the news that the baby was dead. The process of pushing on is the way the women emerged from the tremendous pain of the loss after a period of feeling emotionally overwhelmed. Pushing on led the women to reach out to others for support and helped alleviate feelings of isolation. Even many years after the loss, pushing on is how the women manage to move beyond periods of re-emergence, such as the anniversary of the loss.

Experiencing the Pregnancy

The first process of the theory, Experiencing the Pregnancy, was recalled through the participants’ memories of the pregnancy. Typically, the women put the pregnancy within the context of past fertility issues, or described the pregnancy as planned or unplanned. Some participants discussed planning the pregnancy with statements such as, “My husband and I have been together for 2 ½ years, and we decided it was time.” Others noted apathy, stating, “I wanted to wait a little bit, and then I decided. . . all his friends were having children, so I said, ‘OK, we’ll try.’”

Although motherhood was contemplated and ascribed meaning prior to the actual pregnancy, the story of the lost pregnancy began with the transition from pregnancy as a possibility to pregnancy as a reality. For this reason, the label for first category of the theory was “experiencing the pregnancy” and included three subprocesses: *finding out about the pregnancy*, *developing a relationship*, and *mothering*.

Finding out About the Pregnancy

The first subprocess, *finding out about the pregnancy*, resulted in a myriad of emotions, including shock, surprise, excitement, fear, and dread. When the women discussed getting the news of the pregnancy, they didn’t go into great detail about the precise moment. Rather, they focused on their responses to the news. The majority of participants in the study were excited about becoming pregnant. A few mothers explained that the pregnancy was unplanned and not wanted at that specific time. “I got pregnant and I was like—well. . . I don’t want to be!” One mother who had initially expressed no interest in becoming pregnant went on to say, “It was discussed between us. . . and we chose to have the baby.” It is notable that even very early in the pregnancy, the participant stated, “We chose the have the baby.” This terminology was used by participants regardless of gestational age, indicating that when the women accepted the pregnancy, they anticipated the birth of a live child who would be welcomed into the family. As one mother stated,

When you have a miscarriage people think, “Oh, yeah, miscarriage,” but it’s not just that, [whether] that baby was planned or unplanned, if you want that baby, then it is important, it’s a loss, it’s a baby that’s gone, ya know? It’s a child that’s missing.

Another participant who experienced early pregnancy loss stated, “To me this was a real live person, I didn’t meet her yet, but like, she was my baby.”

Developing a relationship

For the participants, the baby who was growing within them was someone they came to know during the pregnancy. During the subprocess *developing a relationship*, the women described getting to know the baby as a person who was part of the family. Although in some cases the length of the relationship was brief, the women described the development of a unique relationship with the baby and the baby’s place in the family. Statements such as, “It was going to be my second child” (9 weeks’ gestation at loss), “It was the first child in this marriage” (10 weeks’ gestation at loss), and “This was going to be the second grandbaby. . .” (13 weeks’ gestation at loss) indicated that even in early pregnancy, the mothers had already begun to envision how the child would fit into the family structure.

In addition to giving the baby a place in the family, the mothers got to know their children’s gender through ultrasound. Many had named their babies and some had assigned personality traits to their child. One mother who experienced the loss of a twin said, “We had assigned them personalities and we had chosen names.” Another stated, “He was going to be the one who would be a surfer (smiling).” These statements reflected that early in pregnancy, the mothers personalized and individualized their babies. One mother described the uniqueness of a relationship that could not be fully shared. She explained, “To people, it’s abstract. . . you’re pregnant, but I felt [the baby move].”

As further evidence of this developing relationship, the mothers made preparations for the new child. One mother stated, “You start to form a connection, and you have all these hopes and dreams and wishes for this baby and what your life is going to be, and you take time to think about it and plan it out. . .” Another recalled, “We had clothes, and we had this and we had that.” Yet another said, “We were excited. . . we started planning right away.” The participants expected that the pregnancy would result in a live birth, developed a relationship with the expected child, and ultimately took on the maternal role of caring for the baby in utero.

Mothering

Statements that indicated commencement of mothering constitute the next subprocess, *mothering*. Mothering has been defined as “to look after kindly and protectively (Compact Oxford English Dictionary, 2009).” The women discussed acting kindly and protectively toward their babies as soon as they learned they were pregnant, and accepted the pregnancy. They begin taking steps to maintain a healthy pregnancy and incorporated the baby’s needs into their lives. One woman explained, “I kinda wrapped my head around being pregnant and I scheduled, my, um, appointment.” Another mother stated, “I had to watch everything I ate.” A mother noted, “My doctor had told me a couple of times, ‘Make sure you do your kick counts,’ and I had been very good about that, I kept records.” These statements indicated that the participants were looking out for their babies’ well being by taking steps to protect them.

Another aspect of the role of mothering was preparing to expand her family in numerous ways. For example, one mother stated, “We were looking for a new car, so

we're thinking, we need to get a car that's big enough for like, you know, more kids, and, two car seats, and all the stuff." The women actively fostered a loving and caring relationship between siblings. One mother stated, "We would tell her, like, 'Oh, where's the baby?', and she would kiss my stomach. . . she already, she did catch on to that." Another recalled, "She was actually, well, I guess, 22 months when he died, um, yeah, she knew, she knew his name and she would kiss my belly and say 'Baby [name]!'"

For those mothers who had older children, these efforts to foster acceptance of the expected sibling helped them to create a space in the family for the expected child, and helped the mothers transition into mothering the additional child. Thus far in their pregnancies, the women were developing a bond with and mothering a healthy baby. Although they were not naïve about the possibilities of complications, none of the participants stated that they had fears about their likelihood of bearing a healthy live child.

Losing the Baby

At a certain point in the participants' pregnancies, they either began to see clues that there might be problems with the pregnancy or they learned that the baby was in danger. A few mothers learned without forewarning that the baby had died. The women learned from health professionals that the pregnancy was at risk or they noted signs that the pregnancy was potentially troubled. They struggled to maintain hope that nothing was actually wrong. They typically managed to maintain hope that the baby was healthy until they got the news that the baby was dead. When faced with this reality of the situation, the mothers shut down emotionally and were unable to take in the enormity of the pain.

The second stage, Losing the baby, involved four distinct subprocesses: *interpreting the signs*, *getting the news*, *feeling numb*, and *making painful decisions*.

Interpreting Signs

The first subprocess involved *interpreting the signs* of loss. Many of the participants experienced physical symptoms of loss, such as varying degrees of bleeding and cramping that occurred near the time of the loss. One participant recalled, “At about 8 weeks, I had bleeding. . . I started getting cramps, spotting. . .” Another mother stated, “Oh, my God! There was just blood everywhere!” In later pregnancy, signs of loss included a sudden cessation of the baby’s movements. One mother said, “It was my due date and ironically, I ended up coming back, um, because I had noticed no movement.” Another participant described a similar experience, stating, “I noticed he hadn’t been moving much, um, and so overnight I noticed just that it was less and less.”

In an effort to interpret the seriousness of physical symptoms, the participants typically turned to a trusted person for assurance. For example, one woman stated,

I told my husband about that (the bleeding), and um, there was a reaction, he was afraid about that. . . but then very quickly he recovered from that and he said, ‘OK, you know what, we’re just going to keep an eye on things. . .’

Another mother reported, “I definitely mentioned it to [my husband] and, he said, ‘Well, why don’t we wait until the morning. . .’” When the participants made the decision to seek medical care, the response of the health care provider was gauged carefully. One woman explained, “I called my doctor and he said, ‘You better get down here to the hospital.’” She continued, “I probably didn’t say a lot while in the car, I just knew what was happening.”

For some of the participants the first signs of possible trouble came at a routine check-up when, as several mothers noted, “they couldn’t hear the heartbeat.” One participant explained, “I did my first ultrasound and the woman said, ‘The baby seems a little small for the date that you’re saying you got pregnant,’ so of course I started to get a little nervous.” Another recalled, “[The ultrasound technician] said, ‘You’re only 5 weeks’, and I thought, ‘No, actually, I am 8 weeks,’ because I knew exactly when my period was and, ya know, so I knew something was wrong.”

In some cases, the women were not directly informed that their babies were in peril. They quickly discerned others’ nonverbal cues and ascertained the seriousness of events that unfolded. For example, one mother said, “I’ve done ultrasounds before, um, I could see the baby on the screen, but I couldn’t tell anything else. . . . She turned [the screen] away from me at that point.” Similarly, another mother stated,

I didn’t know from the sound, like, ya know, you could hear the machine, I think she turned the volume down, so I wouldn’t have known if there was a heartbeat you could hear or not. . . . It’s just like this moment of, “Oh, my God, what’s happening right now?”

A mother who experienced a full-term loss recalled what was being communicated by the posture of her husband, “I could just see my husband holding his head in his hands. . . . and I knew it was all over.” She also deciphered the behavior of her doctor at the time of the loss saying,

I knew how serious it was when he was doing the internal exam or whatever else he was doing, and um, his beeper was going off seriously, kept going off, going off, and he didn’t even look at the beeper. . . . that kind of got me a little nervous.

Another participant who had experienced a full-term loss recalled her interpretation of the instructions she was given, “They did a sonogram and gave me an envelope to take to the

doctor. . . obviously as the person carrying the child, I already knew that the child was dead. . .”

As the participants interpreted the signs they were receiving from various sources, they tried to maintain hope. This notion is supported by statements such as, “We were thinking, maybe there’s hope,” and “I was still kind of hopeful.” A mother recalled that during an ultrasound, “I could see the [ultrasound technician] taking pictures, so like I’m kinda getting hopeful.” One participant noted the role an online group played in her experience:

As I was reading these message boards about other women who had gone through this and they kept saying, “Have hope, because this is what happened to me,” so we kept thinking, hopefully we’d be the people that this, we’d come through.

Other mothers remembered that their health care providers offered reassurances that encouraged hopefulness, such as “She said, ‘Maybe you’re just off on your dates,’ and I thought that was entirely possible.” The routine actions of the health care providers were frequently interpreted as positive signs, as one mother stated,

The nurse didn’t let on that anything was wrong. . . she even, I remember, fed me lunch. . . I thought, well she’s not going to feed me lunch if they’re gonna be, if I’m going to be delivering babies later.

When discussing her ultrasound, she continued,

The technician who did it, she seemed very grumpy because she said something about being called in on a Saturday and, and I thought, well, this is another sign, if she thought one of my babies had died, she wouldn’t be grumpy towards me.

These feelings of hopefulness remained strong “Even when the doctor had said, ‘You’re likely to lose this baby,’ I thought, ‘No, they’re misdiagnosing me’.” Another

participant said, “We went and I walked in and said, ‘I’m sorry to bug you guys again, but he’s not moving,’ um, ya know, ‘Sorry to waste your time.’”

Throughout this subprocess of *interpreting the signs*, the women picked up on cues from their own bodies, the body language of others, and the words and actions of others. They struggled to make sense of the occurrences and to determine the severity of the situation. In many cases, they maintained hope; in other cases, they refused to believe that anything could be wrong. For all of the participants, at some point, their suspicions that the baby had died were confirmed or their hopes were shattered.

Getting the News

The next subprocess, *getting the news*, began when the mothers received notice from the health care provider that the pregnancy had indeed ended and the baby was dead. One mother recalled, “[The nurse] looked me straight in the face and she said. . . ‘She’s dead.’” Another mother’s experience of this moment was similar: “He wasn’t moving, and I, I could tell when he looked at me and said, ‘I’m sorry, he’s gone, there’s no heartbeat.’” Yet another mother explained, “He came in and he said, ‘I’m sorry, but I have, I have some bad news, [the baby] has no heartbeat.’” A mother who experienced an early pregnancy loss recalled, “They said that there was no heartbeat, ah, that the, the sac had already started to break away. . .” Receiving news of the baby’s death set off a cascade of emotional responses, which together formed the next subprocess, *feeling numb*.

Feeling Numb

The subprocess of *feeling numb* entailed an initial emotional response that was described as shock and disbelief that led to numbness as the gravity of the reality of the loss was acknowledged. Shock was quickly replaced with being stunned by blunted emotions. Some women were unable to take in the information, asking, “What? What do you mean? You mean, ‘He’s dead!?’” like, I had to ask him because I couldn’t even understand what he was saying, and he said, ‘Yes.’” Another woman noted that upon getting the news, she stated, “Well, you’re going to check to make sure again, right?” Likewise, one mother explained, “I kept thinking maybe he’ll cry, ya know, maybe he’s not really dead, and there was nothing. . . just silence (whisper). . .” Another stated frankly, “I could not believe that she was actually gone.” Similar experiences were related with statements such as, “It was just a shock that she was gone,” and “We were still reeling from the shock of it.”

Emotionally unable to face the loss immediately, the women experienced numbness, saying, “I just went numb for a while,” and another explained, “Emotionally, I was numb.” This feeling was emphasized by a mother who experienced the full-term loss of one twin, recalling, “I felt nothing. . . absolutely nothing and I didn’t know what was wrong with me, ya, know, I mean, I didn’t feel anything.” In this state of shock and numbness, the women reported feeling detached from their day-to-day lives, with statements such as, “I just felt like I was on the planet Oz something,” “Part of me was on autopilot,” and, “I felt like I was on *ER* or *Grey’s Anatomy* or something.” Another

recalled, “I just, I felt like I was watching another person.” This feeling of going through the motions was described vividly by another mother who said,

I just said to myself, “Well, just do whatever [my husband] does. . .” So I saw [that he] kissed the baby’s forehead, so when he handed [the baby] back to me, I kissed his forehead and I touched his hand, ya know, I did whatever [he] had done.

One mother deliberately avoided facing the reality of the loss stating, “I feel like I almost put it on hold for a while,” and another noted, “I was afraid of feeling the pain of it.” A mother who experienced a second-trimester loss explained poignantly, “I couldn’t get up to do the shower. . . to look down and see the dead, empty belly.”

As the numbness began to subside, awareness of the physical aspects of the loss began to emerge. Mothers who experienced early pregnancy loss made statements such as, “I felt like something had been torn out of me. . .,” “You’re compromised physically,” and “I was in a lot of pain.” Another stated, “It sucks. . . the hormonal changes and hitting rock bottom, it sucks, that’s all there is to it.” Another recalled, “The recovery was a lot worse than I thought it was going to be.”

Those who experienced late pregnancy losses described intense physical suffering associated with the loss. A participant who experienced a full-term loss experienced uncontrollable clotting and bleeding after the vaginal delivery and was eventually taken for surgery. She recalled,

I kept bleeding and then, um, he, he would have to go in internally and there’d be, ya know, like four nurses around me trying to help hold me onto the table and, and then I was passing like placenta-sized clots, um, so. . . he ended up having to take me into the OR to do a, a D & C and. . . I, of course, was just so happy he was putting me out cuz that was so painful.

Another recalled, “The C-section was, ya, know, awful. . . major surgery.”

During this period when numbness was decreasing and the intense physical suffering was increasing, some women were faced with making decisions about their care. One mother recalled her experience stating, “[The doctor] said, ‘We’re going to have to deliver him. . .’ [They] started the induction. . . broke my water. . . and said, ‘Do you want some drugs?’” Such questions forced the women to become engaged in the process of *making painful decisions*.

Making Painful Decisions

As part of the subprocess of *making painful decisions*, the women were forced to deal with the tasks at hand, and were suddenly wrenched away from the shock of the loss and the numbness they were experiencing. In this fragile emotional state, the women were compelled to make decisions quickly regarding their physical care and the care of the baby’s body. One participant described this experience, saying, “I felt like we just hit a brick wall.”

Shortly after finding out that her baby had died in utero, one mother described her physician as giving her options about which she had to make decisions quickly: “You could go home or I can admit you now. We’ll induce you now and you can deliver him, and I just said, ‘Ya, let’s do that.’” Another participant who experienced a first-trimester loss recalled the office staff saying,

“Here’s what we can do, we can get you scheduled in with the doctor . . . and he can do the surgery, we can squeeze you in at the hospital,” and ya know, “Here’s the coverage, and here’s this and here’s that . . .” and I was kinda like, “Aaaah, ok.”

Another mother who experienced a first-trimester loss was quickly presented with treatment options but refused, stating, “My body knows what to do and it’ll do it.”

Mothers who experienced second- and third-trimester losses had to deliver their babies either vaginally or by cesarean section and were usually asked whether they wanted to see their babies. One mother recalled the nursing staff asking, “Would you like us to bring in [the baby]?” When faced with this decision, another mother who experienced a full-term loss recalled,

Initially neither of us did. . . My main concern was thinking that something was gonna be terribly wrong with her and that she was going to be all disformed and disfigured and that, that vision would haunt me for the rest of my life.

The mothers described their experiences of holding their babies as positive, noting, “She looked perfect, she came out perfect, there was nothing visibly wrong with her,” and another said, “He was a perfect little person.” Another mother recalled, “We held him and looked at him, he looked just like my husband.” The emotional burden of seeing and holding their lifeless children was evident in statements such as, “I told them that they had to take her because I was holding her and I said, “If I hold her any longer, you’re not gonna get her from me.” In these painful and poignant moments, the women were also expected to make decisions quickly about autopsy and funeral arrangements.

One mother recalled, “I had to make a decision within 24 hours because they were disposing of the body.” Another mother was told, “‘You need to decide if you want an autopsy.’ I said, ‘No, I don’t want to do that to his body.’” The demand for such decisions caught some of the participants off guard. One participant stated, “The nurse said we needed to think about what funeral home we wanted to call, and my mom was

like, ‘Oh my God, we have to have a funeral!?’” Similarly, another mother remembered, “I sat there with the nurse and already I was making arrangements for [the baby]. . . It’s kind of shocking to me that I, ya know, did that. . . The loss hadn’t hit me yet.” The women struggled to deal with decisions regarding their own delivery and aftercare while making critical decisions regarding the baby. As the women’s emotional numbness began to fade, they began bearing the burden of their loss

Bearing the Burden

The fourth stage of the theory, Bearing the burden, began when the women realized that they had to inform others that the baby had died. One mother recalled the moment she realized she had a responsibility to explain the loss to her other children, saying, “[The other children] started hearing little bits of us talking and they knew I was upset about something. . . And then all of a sudden we realized, oh crap, we gotta tell them something.” One participant explained the death to siblings by stating, “We just said that she went, the baby went to heaven.” Another stated, “We say that one of your sisters is an angel.” Upon breaking the news to others, the participants described being faced with the following subprocesses: *comforting others*, *apprehending the loss*, and *succumbing to grief*, *searching for answers*, and *feeling frustrated*.

Comforting Others

The first subprocess, *comforting others*, was characterized by the participants’ realization that after breaking the sad news to others, they had a responsibility to provide support. One mother recalled, “I just felt like the burden was constantly on me, to make other people comfortable, and, in fact, they should have been making me comfortable!”

Another remembered, “[My husband] crawled up in the bed next to me and started to sob. . . I was kind of comforting him. . . but I didn’t have anything left.” Another explained, “You’re bearing their burden of grief but, again, sometimes you have to be the strong one.” Likewise, another participant recalled supporting a family member, saying, “We talked a little bit more about it. . . I wanted her. . . not to be overwhelmed by her sadness.”

Sharing the news of the loss with other family members and friends fostered awareness of the magnitude of the loss. The participants began to place the loss within the context of their lives and the lives of their loved ones. This awareness indicated the next subprocess, *apprehending the loss*, had begun. It was a period marked by recognition of the numerous aspects of their lives that were affected by the loss.

Apprehending the Loss

One participant recalled her husband’s response to the loss, saying, “I remember [he] started sobbing, he was sitting in the rocking chair in the maternity room and he was just holding this little baby and he was sobbing.” Another stated, “My husband, he couldn’t be by my side through the whole surgery, so it was probably 10 times worse for him.” One mother said,

I think he felt he had to be strong for me and that’s what he did, um, because he saw [the baby] till the last, which, like, he has that memory and I don’t and I don’t know how he handles that, but he does.

As the participants gained greater awareness of the effect of the loss on others, they were often struck by the siblings’ struggle to understand the loss of their anticipated new brother or sister. One mother explained, “She asked me. . . ‘Did he die?? My brother

died?’ Obviously that. . . breaks your heart, ya know?’ Another mother recalled, “They were really sad and they were crying and they were upset,” and another said, “I remember her crying. . . It was her first exposure to death. . . in her world, it was a death.” And one mother described how siblings comforted each other at the time of the loss: “She cried. . . I remember [her younger sibling] saying to her, ‘Eess ok, eess ok.’”

As their awareness of the enormity of the loss grew, the participants also became aware of other hardships related to the loss, such as paying for needed services and managing time off from work. One participant recalled, “I decided to go to bereavement counseling. . . a friend [of my family] said she was willing. . . to do it for free. . . I couldn’t have paid for it at the time.” Another described the burden of the medical bills that she received following the loss:

All the bills that I received after the D & C. . . things are going to collections and it’s just an absolute nightmare. . . I really cannot deal with these bills ’cause they remind me of the, the pregnancy losses.

Another participant described her financial concerns, stating, “I went right back to work, and um, that was because I had already taken a maternity leave. . . I couldn’t afford another one.”

Although returning to work was necessary financially, it was cited as emotionally trying for some women. One participant explained, “For me, it was, ‘Ok, back to work. . . and pretend everything’s fine. . . like that I was never pregnant and I never lost a baby.’” Another explained, “I went to a meeting and there was a woman there who had also known I was having twins and she saw me and she had a big smile and. . . she was just walking by in a crowded room of people and she just said, ‘How are your babies?’

And I said, ‘Great!’ . . . and I just thought, well, there’s nothing else I could do, because I can’t say, ‘Well, hold on a second, actually, one of them is not great. . .’ I cried all the way home.”

For those who worked with children, returning to work after the loss was especially problematic. One participant explained, “I let my, my boss know because I work with small children and babies—I let them know that I was having a really hard time. . . I asked for a mental health day. . . I couldn’t, I couldn’t handle it.” Another explained, “I couldn’t even be around children, like small children, I was very upset. . . I couldn’t explain it, can’t explain it.” Likewise, another noted,

It was hard to look at some of (the clients I work with), um, who have many, many children, and um, their children are treated very poorly, um, that was very difficult, um, so I think, ya know, for a while it made me a little more angry at work.

As the women became increasingly aware of the consequences of perinatal loss on their lives and the lives of their loved ones, they eventually reached a point when the burden became too great to bear and the women felt the need to give in to the suffering. This new awareness was described by one participant 4 months post loss: “I think now, now I’m kinda letting myself feel the pain a little bit more and just kinda letting myself be sad about it.” Such acknowledgements that the inevitable pain of the loss was upon them denoted the onset of the next subprocess of this stage, *succumbing to grief*.

Succumbing to Grief

Shortly after the loss, some mothers described physical aspects of succumbing to the grief that they expressed as having a sense of continuing to be pregnant, “I had phantom kicks for quite some, could still feel him kicking.” Lactation after the loss, and

“looking pregnant” were also described as painful reminders of their loss. One mother noted feeling the need to hold her child, stating,

[Around the] due date. . . I suddenly felt like my arms were aching for a baby more. . . I was having weird cramps. . . I think my body kind of was thinking, ‘Ok, I’m about to give birth now’. . . Even though I lost the baby, at some level there’s something in the body that, that remembers. . .

Although the physical aspects of the loss subsided over time, the women described an ongoing emotional pain and sadness that was most intense during this subprocess.

Emotionally, the women experienced intense sadness, guilt, anger, and isolation. Some of the women also expressed fear of subsequent losses. The mothers typically described a poignant moment at which the reality of the loss became overwhelming. One mother recalled,

I came back from the hospital. . . and somebody came out of the elevator with a toddler (sobbing) and I just, I just stopped. I couldn’t, I couldn’t walk, I couldn’t walk because that was my future that was gone.

A mother who lost one twin explained, “[My husband] put up a big sign that said, ‘Welcome home Mommy and [baby]’. . . and I thought, ‘Where’s [the other baby]’s name (sob)?” The sadness and emptiness experienced by the women was evident in statements such as, “I felt. . . sad after the loss,” and “I was soooo down and out.” For some women, this sadness lingered:

The first couple of weeks there, I didn’t want to get out of bed, I cried all the time. We would be in the middle of dinner and I would cry. I was just, it was just a sad situation.

Other mothers described crying over the loss, saying, “I had cried so much,” and “I’m sure I cried a lot.” Another recalled, “It was, honestly, just a lot of crying.” The sadness and crying were often accompanied by exhaustion and emotional pain.

One mother explained, “I can tell you that this hurts really bad (sob),” and another said, “It’s more emotional than anybody could ever conceive of.” The depth of the pain was expressed in statements such as, “It just cut me to the deepest place you can get to,” and another said, “The depth of [grief] is endless.” Likewise, another participant explained, “Every moment, it’s, ‘My baby’s dead,’ ya know, this doesn’t matter, none of it matters.” In these dark moments of suffering, the mothers were unable to function in their usual roles, and made statements such as,

It was raw and awful for, I guess, I don’t know, 3 or 4 months, um, where I mean it was all-consuming, that’s all I thought about, all the time, I couldn’t function or anything, couldn’t worry about anything else, couldn’t think about anything else.

This particular mother continued, “At the lowest point of grief, I mean, you can’t really function, all I wanted to do was sleep and have the pain go away.” Another participant explained, “For so many weeks, I would wake up in the middle of the night or the morning and the first thing I thought of was the baby,” and another stated, “I was just truly overwhelmed.” Another mother said, “I couldn’t pick myself back up. . . I was crying all the time.”

The grief that followed the loss manifested itself differently in different women. For some of the participants, the loss brought on feelings of fearfulness about the unpredictability of life, and the safety of their loved ones. Many of the women described being fearful that peril and death could befall their loved ones without warning. This fearfulness applied to life in general, and also extended to feeling fearful about subsequent pregnancies, the pregnancies of others, and the safety of their subsequent children. Describing this new awareness, one mother stated,

You realize how much of life is lived by illusion, the illusion that we can safely cross the street, the illusion that we can safely take an airplane, that we can safely drive to the mall. . . we live by illusion and we need to live by illusion.

Another mother was shocked by the realization that “a baby could die, just out of the blue.” The unpredictability of life caused some to fear for the safety of their other loved ones; one participant noted, “If [my baby] could die, anybody could.” Some of the women began to feel vulnerable to other losses, and became fearful that “something bad is going to happen.” One mother explained, “When you have a loss like that, it makes you very suspicious in general, about viability, like, your husband’s late, he probably got killed in a car accident, that kind of thing.” Another echoed this sentiment, stating, “I worry about [my husband] with his commute, I think something’s going to happen to him.” In addition to worrying that they will suffer another devastating loss, the women became more cognizant of their own mortality. One participant explained, “I really did think I was going to die, so I was pretty freaked out,” and another stated, “[You’re] terrified about your own health.”

In addition to becoming fearful of losing others to death, the participants worried about the possibility of breaking up with their partners. One mother recalled a conversation with her husband, saying, “I couldn’t really sleep and I just started crying. . . I said, that, ‘Things like this can, ya know, drive people apart. . . Are we going to be ok?’” Likewise, some of the participants worried that their husband’s view of them would change, and made statements such as, “If this happened two or three times, would he be this supportive. . . granted, you’re supportive now, but then are you looking at me like

something's wrong with me?" Others conveyed similar worry: "The statistics, for a loss of a baby, and a successful marriage, um, not very good."

The participants' views of subsequent pregnancy were also changed by the experience of loss. The women no longer saw pregnancy as a period of joyful anticipation. Rather, they came to believe that loss is common and that "pregnancy [is] fraught with danger." Others commented that "pregnancy doesn't always equal baby" and one mentioned that she had become

frustrated with friends. . . that are pregnant, and, ya know have these 'plans' where they want to get pregnant, ya know, and they have these 'plans' and everything is going to go according to their 'plan', um, that makes me crazy.

One participant stated, "One of my friends announced that she was pregnant and I was like, 'NO! Don't tell anyone!' um, so yes, I guess I'm more aware of how fragile pregnancy is."

With their new awareness regarding the fragility of pregnancy, some of the participants reported hypervigilance during subsequent pregnancies, stating, "I made sure I did everything I was told." One mother recalled, "When I got pregnant the second time, I was a bit more careful." Another stated, "I think maybe I gotta take it easy now, I lost one and I don't want to lose another one." Mothers were generally more anxious and made statements such as, "Every little thing that goes on, I think, 'Oh, my God, there's something wrong, there's got to be something wrong.'"

Sometimes the participants who felt "vulnerable" during pregnancy sought medical care more readily than they had done during the previous pregnancy. One mother explained, "I panicked and they got me an appointment right away to see [the doctor]."

Another stated, “I was scheduled for cesarean. . . just to avoid what might have happened in the last week or two.” A mother stated,

[Before the loss], I just felt resilient, yeah, I’m young, we shouldn’t have any problems having kids. . . I guess it opened my eyes to think, yeah, this is reality and, ya know, anything could happen at any time.

For most of the participants, the anxiety they felt during subsequent pregnancy diminished after the birth. One mother stated unequivocally, “I felt safe after he was born.”

Other mothers continued to experience anxiety about the safety of their subsequent children after birth. One mother stated, “We’re both freaked out, we were worried mostly about SIDS. . . We have a really good video monitor and we could watch it and make sure. . . several times a night.” Illness provoked extreme fear among some parents, as pointed out by one mother who stated, “She was so sick. . . and I was sure she was going to die. . . I held her hand all night because I *knew* she could die.” Another mother recalled, “He was sick. . . but I totally overreacted. . . I remember saying to [my husband], I just sat there and said, ‘He’s going to die.’” Others experienced similar fear, but to a lesser degree, which resulted in protective parenting. One mother stated, “We’re very protective of [our son] because of that,” and another said, “I was protective anyways, and then when this happened, it was like, nobody’s getting near this child.” Statements such as these reflect the mothers’ reactions to the burden of the loss, and caused them to question why such a terrible fate had befallen them. The women’s quest to find answers indicated movement into the next subcategory, *searching for answers*.

Searching for Answers

The pain and fear that ensued following the pregnancy loss left the women questioning why this terrible fate had befallen them. This turn denoted the transition into the next subprocess, *searching for answers*. The mothers began to search for a reason for their child's death and made statements such as, "I wanted to know why this happened," and "He was a perfect little person and he, why did he die?"

The women described their attempts to find answers: "I called my doctor's office a couple of times, ah, ya know, looking for these autopsy reports." Regardless of whether a medical explanation for the loss was available, the women mentally reviewed the days and hours preceding the loss and began to wonder if they had inadvertently done something to cause it. They expressed feelings of guilt and blame in statements such as, "I feel like all the stress that was going on in our lives contributed to the loss," "Could exercise have done it?" "What if I had gone in 24 hours sooner?" and "I actually didn't count kicks, I'm pretty sure, on Thursday and Friday." One mother stated matter-of-factly, "I blame myself." Others questioned their actions prior to the pregnancy in statements such as, "Was it because I was on the pill before?" "Was it the medication I was taking, did I not eat enough, did I not drink enough, did I not sleep enough?" and "Did I do anything? I [was] picking up my son, and he's a heavy kid. . ." Another mother questioned, "[Was it] the glass of wine or, ya know, [did I] dance too long on the dance floor? I mean, I didn't take my vitamins for 4 days. . . you just find anything and think, 'What did I do?'"

In their quest to determine why the loss occurred, the participants turned to numerous sources, including health care providers, books, and internet sites. One mother explained, “I’ve read every article online that there could be. . . I’ve read books constantly just trying to find, it’s like, that answer, ya, know, what did I do wrong?” Another shared the same sentiment: “I tried to research this myself, I did a lot of reading about it.” Unable to find an explanation for their suffering, the women expressed frustration and sometimes anger. The next subprocess, *feeling frustrated* includes women’s descriptions of their responses to the perceived insensitivity of others, which sometimes led to emotional outbursts.

Feeling Frustrated

In the subprocess of *feeling frustrated*, the participants were no longer overwhelmed emotionally; they had gained emotional resiliency and began to express their frustration. One mother explained,

I felt gypped, I felt it was unfair, ya know, like I went through this whole thing, I went all the way to the end, so now I have like all this. . . extra fat, I’m covered in stretch marks. . . and what did I get for it? I guess I did get a child out of it, but she’s not here, ya know, so that was hard.

In some instances, the women were frustrated to the point of anger. A participant explained,

There was a lot of anger after the baby died, any kind of grief, there’s a lot of anger and the problem with us is, 9 times out of 10, there’s nowhere to place the anger, ya know, the baby died and nobody knows why and it’s nothing anybody did or didn’t do, so you get angry at yourself, you get angry at the doctors, then you can’t get angry at the baby, but you can. . . so you have a lot of misplaced anger and that’s hard.

Although some participants expressed misplaced anger, others discussed feeling upset and angry when their loss reactions were misunderstood or minimized. One mother explained, “[A friend] had so many early miscarriages, and. . . after a while, she was just like, ‘Okay, ya know, move on,’ and I was like really stuck on it for a while.” Another participant expressed similar sentiments, saying “Everyone thinks you should move on. . . it doesn’t work that way.” The women described feeling frustrated by the reactions of others, and by not receiving the support and care the loss warranted. Often, the women were frustrated to the point of anger, and lashed out at others when provoked.

One mother recalled a heated conversation with a family member saying, “Every time I would suffer a miscarriage. . . she would really blow it off. . . Finally, I said, ‘You know what?’ This is a child. . . I really laid into her.” Another mother said, “My mother said something about [the baby] being in limbo and I nearly hit the roof like, ‘How could you say that!?’ I mean, it’s such a ridic. . . the whole idea is ridiculous!”

Sometimes health care providers were the target of a bereaved mother’s anger: “Unfortunately. . . I just went back and just started yelling and screaming at this poor nurse.” Although the anger tended to fade over time, some of the women reported that a lack of ongoing emotional support sometimes spurred lingering bitterness. One mother explained, “In the beginning, everyone is wonderful and supportive, but everybody else moves on.” She continued, “It’s still a big thing for me, it’s not for everyone else, ya know?” Marital discord often resulted when the women felt ill-supported by their partners. Eventually, the women recognized that their partners had different needs, stating, “We don’t always feel the same things at the same time,” and another said, “I

know that he was hurt, but he didn't ever cry, he didn't talk about it a whole lot, he internalizes things a lot more. . .” Some of the women were frustrated by their partners' responses to the deaths of their anticipated children. They perceived their partners as either unwilling or unable to work through the grief with them, stating, “I wanted him to grieve with me. . . so I do remember that being a difficult part,” and another recalled telling her spouse, “I need to know that you're sad, too!”

Over time, the women could not sustain the emotional energy needed to maintain their frustration, anger or sadness. They reached a point at which they had to let go of that emotional burden. One woman stated, “You don't want to live there. . . you have to let that go.” Another mother concurred, saying, “It was kinda like another soul went to heaven, and I, we just had to let that go.” Still another participant stated, “She was my baby, and I knew, like, she's in heaven, and I had to just believe that and let go of it.” They recognized that their distress was taking a toll on their lives, and that their social, professional, and financial responsibilities were inescapable. They became acutely aware of the need to overcome their pain and to return fully to their former roles. To do this, the women actively sought ways to work through their distress. The next stage, Working through the pain, denoted the participants' active efforts to move beyond their suffering.

Working Through the Pain

At this stage of the theory, the participants took steps to let go of some of their pain and to return to their roles as mothers, wives, daughters, sisters, and coworkers. This stage involved a conscious effort by the participants to resist becoming overwhelmed by

their sadness, to take hold of it and to work through it. Working through the pain involved four subprocesses: *letting it go*, *engaging again*, *seeking help*, and *reflecting*.

Letting it Go

In the first subprocess, *letting it go*, the participants let go of much of their pain and anger by forgiving themselves and others. Reassuring words from others, particularly health care providers, helped the women to overcome feelings of self-blame. One mother recalled, “The doctor said it wasn’t my fault, I didn’t do it, um, so yeah, she definitely helped me.” Another mother noted,

One of the first things the nurse said, like, ‘Don’t think it was your fault, you didn’t do anything’, and to know that there was something that was like, from the moment of conception, this baby was just destined to be the way she was, it was, it was something that was just taken out of my hands and it helped so much, like, to know that.

Such helpful information and assurance enabled the women to move beyond the pain.

As the women began to move beyond the pain, they reached a point at which they were able to forgive others by rationalizing their behavior. Typically, they cited misunderstandings about pregnancy loss for the poor responses of others, and made statements such as, “Nobody understands what I’m going through.” Although statements such as this are often viewed as a call for awareness, in this study, similar statements are seen as a milestone for the women having achieved some degree of emotional healing.

Since part of *letting it go* is providing an explanation for the behaviors of others, several women rationalized the behaviors of others through citing cultural norms. Cultural norms helped the women explain the mismatch between the support they wanted and the support they received. Several women interpreted the support they received from

the cultural perspective of their Irish-American backgrounds, which is reflective of the area in which the study was conducted. One participant recalled,

My brothers, who are great guys, but not terribly, I mean, they're Irish guys, so they're not terribly emotional, um, were crying, and when they, the first time they saw me, even if it was 2 or 3 weeks after, um, ya know, we're doing that long hug and just saying, 'How are you doing, are you OK?' . . . I found that enormously helpful.

Another participant recalled,

My mother is not warm and fuzzy, ah, she's a very loving person but she's not kind of, ya know, she's, she's a daughter of Irish immigrants and they, the attitude was kind of you suppressed your emotions, ya know, you hide things. . . The idea of openly expressing grief about a baby who was stillborn, ya know, who never even lived, ya know, I think that is kind of strange [to them].

One mother noted,

Initially, I, I didn't want anybody to come [to the funeral]. . . but my husband has a very large, Irish Catholic family. . . they get together for everything, which is a wonderful thing, um, but. . . I kinda struggled with that. . . I just didn't want to be around, ya know, everybody. . .

The women's reflections on the effect cultural heritage had on their grief responses and the responses of others suggested that they understood the perspective of their family members. Likely, a woman's cultural background influences her own response to loss as well as her interpretation of the responses of others. Gaining an understanding of why others responded as they did was a hallmark of the subprocess of *letting it go*.

Engaging Again

The subprocess of *letting it go* allowed the women to stop spending emotional energy on anger and blame, and gave them enough emotional space to begin the next subprocess of *engaging again*. The subprocess of *engaging again* was described as a

point at which the women consciously decided that they could no longer continue to carry the heavy burden of their grief. They discussed feeling “just so tired of grieving” and tired of “dealing with the loss every single day,” which was expressed by several participants. They recognized that their grief weighed heavily on their hearts and minds, and was affecting others as well. One mother explained,

I wasn't living with the same joy and happiness and, like, you know what I mean, that same freedom that I did before and, for a while it felt like that and, like, I feel, just in the past couple of weeks, I started to come out of that a little bit.

Recognizing that their grief was preventing them from engaging fully in life gave the women a reason to work through the pain. They recognized the need to return to their former roles and actively took steps to re-engage in their former lives. To do this, the mothers harnessed deep inner resources to take hold of their pain, willing themselves to move beyond the suffering, which was described in statements such as, “You have to do this, you have to,” and “I’m trying, I’m getting better,” and another simply stated, “Ya gotta do what ya gotta do.”

This determination to re-engage in life inspired the women to slowly refocus their energy on their other children, their spouses, and their jobs. One participant explained,

[I] slowly just kind of, I guess, came out of it and I think having two little kids at home, I mean, [my son] was a baby, [he] was like a year old. . . um, I had to shift gears pretty quickly back into [life].

Another expressed similar sentiments, stating, “It was harder to be the carefree mom I was before. . . I have to be aware of that and make sure I still give her time and attention and fun, even if I’m not feeling like it.” Becoming involved again in usual activities also distracted the women from their pain, which they felt helped them to work through it.

One mother described how having another child at home helped her to move beyond the pain, stating, “[He was] just 2 years old and so he just gabbers away and, ya know, and I said ‘Great!’ That’s just what I need (laughter).”

For other participants, returning to work helped to ease the pain, which is evident in statements such as,

You feel that somehow you are not whole, so you have to pursue something in which you would excel and that for me that was [work]. . . it is very affirming, ya know, and to be able to do well at something.

Another mother concurred:

[The pain] lessened a little and gave me a little bit of hope, um, and slowly, as the months went by, it got where I still thought about it all the time, every day, but I could focus on other things. I went back to work and I could do that.

The women noted that engaging again in life as a bereaved mother would involve reaching inward to find strength and outward for support. They described the process as a turning point saying,

I finally called a friend. . . who had been through the same thing, I meant to call her for months. I finally called her and we talked and just, the connections with other people, ya know, I had kinda backed away from them at the time when I really needed them. . . so I’m trying to reach out again.

Similar statements denoted the third subprocess of this stage, *seeking help*.

Seeking Help

When the women realized that they weren’t receiving the support they needed from others, they began an active process of seeking help. *Seeking help* took many forms including giving and receiving emotional support from the partner, talking with other women who experienced loss, seeking online support communities, and face to face support groups. *Seeking help* was reported as the most useful way for mothers to ease

their grief. The women believed that their husbands had the best understanding of their pain and were determined to work through the pain with them, stating, “We relied on each other.” One mother stated, “We had to deal with [the loss] together.” Another participant recalled grieving with her husband, saying,

For the first couple of weeks. . . we’d have a conversation and one of us would end up crying. . . I had to push him and like ask him to share stuff with me. . . I know he’s just looking out for me, but I have to remind him still, ya know, let me in.

Talking to each other helped married couples gain an understanding of each other’s feelings. Some mothers described this experience, stating, “Talking to each other about things [helped],” and another said, “We talk about it all the time.” Another participant explained, “[My husband] said to me, ‘I can never feel everything that you felt because you knew her better,’ which is true. He didn’t feel her moving, he didn’t see her on the screens.” Another participant explained, “I felt like I lost a child; he felt like we almost had one.” Over time, though, the women noticed that their partners were no longer able to discuss the loss. These sentiments were expressed by one mother as, “For me, talking about it [helped]; for him, that was a little early on. . . ya know, no more.” One mother explained that during times of disunity, the support of her friends, “helped for us to just recognize in each other, this is what [I] needed, and this is what [he] needed.”

Such guidance from female friends helped the women to gauge their own progress. As one participant recalled, “[My friend] was the one who pointed out to me, like at the end of 6 months, that I was still kind of wacky.” Often the participants found comfort in talking with others who had experienced a similar loss. Many women described informal networks with other women that alleviated their feeling that no one

understood their experience, or that something was wrong with them. Sharing their stories helped the participants to “[gain] perspective” and alleviated feelings of isolation. One mother stated, “Talking with other mothers. . . you realize that this is common.” Another related, “Everyone had [a loss] themselves or a close family member. I had no idea how common it was. . . it was really, ya know, comforting in bizarre sort of way.”

Talking with other women allowed the participants to compare their losses with those of others, which they found helpful. Many of the women talked to friends or family members, but some of the participants sought formal support networks through face to face groups, which served the same purpose as informal networks. One mother who attended a formal support group stated, “Hearing everybody’s different stories and perspectives, I really think they put it into place.” Sharing stories of loss with others eased the participants’ isolation and changed their perspectives on loss.

One participant explained, “I always thought what I went through with my first son. . . was so horrible and then [after I heard her story], I thought, ‘God, I’m grateful I didn’t have to go through that.’” Another mother compared her early loss to another woman’s late-term loss, saying, “She carried her babies much further than I did. . . she was able to see their faces. . . so I could not imagine the pain of carrying the baby to term and then coming home with nothing.” Another participant stated, “It’ll never make sense to me. . . at the same time, I don’t know if I could have handled [a full-term loss] emotionally, to have to pass a baby naturally.” Conversely, a mother who experienced late loss felt more fortunate than those who had early losses, stating,

I went full term. . . I think people’s responses are, are different than, than say, somebody who has an earlier loss. I think it’s a loss no matter what. I think that

people put a little more gravity in [late] loss, so that, um, the support and the caring. . . that made it easier.

Another mother stated,

Miscarriages. . . in people's minds, well, it's not really, "Okay, you're sad, you can be sad for a week and then that's it," ya know. . . when [my daughter] died, it was almost like I was allowed to grieve even longer because she's actually in a cemetery.

Through considering their own experiences of loss in relation to those of other women, the participants came to believe that the experience of losing a child has lasting effects regardless of gestational age or time transpired since loss. One mother stated,

There's really no difference, as soon as you know you're pregnant, pretty much everybody, you plan and have plans and hopes and dreams and so that baby is just as real at 6 weeks for you as it is at 23 weeks and 3 days for me.

Sharing their experiences with others who had lost a child allowed the participants to form a bond even if the loss was that of an older child. As one mother explained,

The whole experience brought us a little closer. . . she lost a child. . . a toddler. . . in a car accident. . . a different kind of loss, but still a child loss, so we've kinda had that bond.

No longer isolated and alone, the participants gained strength from telling their stories, and actively sought others who would listen. One participant noted, "I found other people who were willing to talk," and another stated, "I talk about her and I kinda force some people around me who don't want to hear it to listen because they're a captive audience that makes me feel better." In addition to face-to-face conversations, the participants reached out to other women over the Internet. One mother noted, "I think the thing that helped me the most was just honestly connecting with other women online to see what their experience was." Bonding with other women alleviated feelings of

isolation and provided social support, which the women cited as helpful. As the intense pain of the loss began to subside, and the mothers felt emotionally stronger, they began to reflect on the meaning of the loss, which denoted the onset of the next subprocess:

reflecting.

Reflecting

In the subprocess of *reflecting*, the mothers recalled looking back on the loss and their pain and “reflecting on it.” Through reflection, they developed a belief that they had actually been spared a worse fate, which fostered feelings of gratitude. As one mother explained, “If the baby had lived longer, this might have happened later in the pregnancy or if the baby had been born. . . or had serious, like, difficulties. . . so, it was a relief.” Another mother whose child had been diagnosed with multiple anomalies explained, “She wouldn’t have had very much of a quality of life. . . she might have been on life support, and all that, so I felt like we were spared a lot of misery.” One participant said, “I can see now that maybe that was a blessing.” Still another participant recalled,

It could have gone a different way in which, if he had lived and been hooked up. . . we were able to talk to each other and say, “This is probably the best,” ya know, quote, unquote, “scenario for us,” and we couldn’t have been able to deal with [a different outcome].

Another mother echoed this sentiment, stating,

I don’t know if I could, honestly, with my temperament, um, raise a child with physical needs, special needs, so ya know, God was protecting me to say, ya know, there was something wrong with this child that you wouldn’t be able to handle.

Even mothers who lost one full-term twin expressed similar feelings, stating, “I just thought the worst thing has happened, ya know, I lost a baby. I guess the worst thing

would have been if I lost both of them.” Another mother said, “I was so grateful that she had lived as long as she had because we would have lost the other twin.” Despite her sorrow, she recalled,

Now I can look back and I can say, wow, ya know, there were happy times in the hospital. . . I remember touching her toes, and I remember looking at her face, and I remember seeing how much like her sister she was.

Another mother similarly glimpsed joy through her sadness, saying, “I don’t regret that it happened, I feel like he was a blessing to us and while he was alive, we had great joy (sob).”

As the participants began to focus on the life that was lived rather than the life that was lost, they reflected on mementos. Cards bearing the babies’ footprints and handprints, photos and ultrasound images, and baptism shells helped the women to take hold of the reality of the loss, and provided a tangible means of connecting with their children. One mother stated, “They did his footprints and ya know, they were really good because it’s another validation thing that we had this baby and he was here and he lived and he died.” Another reflected on the importance of photographs, “[My husband] took pictures of [our son] which I value greatly because in the picture he looks perfect. He doesn’t look dead.” One participant described the meaning of an ultrasound picture saying, “At least we saw [the picture]. . . that’s all I really have left at this point.”

One mother discussed the meaning of a special memento from the funeral director, saying,

They scan the handprints and the footprints at the funeral home and there’s a company that makes jewelry out of it. . . I feel like, “Ya know, okay, well, I have something of hers always then, like, on me,” ya know? So that’s a nice thing.

Reflecting on the loss allowed women to transcend the intensity of their grief and transform their sorrow into finding meaning and purpose in getting on with their lives despite their loss. Over time and through reflection, the women were able to let go of more and more of the pain and began to view life in a new way. They began the final stage of the process, Transcending the suffering.

Transcending the suffering

The study's participants had worked through much of the pain of the loss and begun to re-engage in the activities of life. The processes of experiencing the pregnancy, losing the baby, bearing the burden, and working through the pain, changed existentially and recognized that they would "never be the same." They had been devastated by the loss, and had risen above their grief, emerging with a new perspective on life. They reported generally feeling stronger, more compassionate, more appreciative, and more understanding of others' losses.

The process of maternal perinatal bereavement culminated in permanent existential changes when the women were able to transcend the grief. For example, one mother noted, "That was a major stressor to me and I was able to get through it, without medications, without anything, and I felt, ya know, good, ya know, I can do this." Another mother concurred, stating, "It makes you stronger, what won't kill you makes you stronger, so it's definitely changed me in that way."

It should be noted that not all of the participants had reached the stage of Transcending the suffering at the point in time at which the interview with the researcher took place. Those whose losses had occurred recently were still in the early part of the

process, and did not report the changes that those who had transcended the grief discussed. Typically, the women who experienced late pregnancy loss reached the final stage, Transcending the suffering 9-12 months after the loss. Mothers who experienced early pregnancy loss reached this stage sooner, by 3-6 months. Also notable is that the inner change women experienced altered their approaches to people and situations, resulting in a new way of being. In other words, the final stage of the substantive theory of maternal perinatal bereavement discovered in this study is a permanent, but incomplete state, an ongoing process of transcendence which involves three subprocesses: *longing*, *making sense*, and *becoming*.

Longing

The first subprocess of Transcending the suffering, *longing*, involved feeling the ongoing absence of the baby at various times during the women's lives. For some women, this emptiness was ever present, as one mother stated "I'm sad all the time, it never goes away," and another likewise noted, "This is [many] years later, and look at me now, ya know? (crying). I still have the loss; it never goes away." These statements indicated that the mothers continued to miss the lost child and to long for the child's presence in their lives. One mother stated, "You have this longing for this child that's not there, it's very intense." Several mothers described physical components of missing their lost babies. One mother said, "The grief eventually does not paralyze you," and another stated, "It's not that it gets better, it changes." And another explained, "It's always there, it's never gone. . . you never get over it, you don't get past it, you just live with it."

Although the intense pain of the loss slowly decreased over time, and by Working through the pain, the women continued to experience periods when they were acutely aware of their child's absence, and in those moments, the pain re-emerged. One participant explained, "It gets worse around birthdays, or obviously Mother's Day, it's tough, then Christmas, and any holiday, really. . . it opens the wound again." Likewise, another stated, "Around holidays, special events, certain dates that I remember and definitely leading up to the birthdays, it's really very difficult, very difficult." Another recalled,

I was very conscious of the anniversary of the miscarriage, just, ya know, when the baby was due, what would it have been like, ya know? The baby was due around Christmas time, but we didn't have a baby around Christmas time. . . so, those moments, I probably even kind of went more into myself.

And another woman described a similar experience saying, "Every year on his anniversary, ya know, I have a good cry." Some mothers recalled an upsurge of grief during subsequent pregnancy, stating, "I went deeper back into the grief right before [the delivery], and then going into the delivery room, ya know, I think that triggered it all." Another mother said, "Getting pregnant again brings a whole lot of it back up again."

The participants described triggers that were not directly related to their own children, such as news stories about child neglect and abuse. One mother explained, "Any neglect of children on TV that I see just kills me obviously, and ya know, these women don't want their children and they have them healthy and mine died. . . ya know, the injustice triggers it." Another expressed similar sentiments, stating, "It was hard to look at some of these [people] who have many, many children and their children are treated very poorly." Another participant put it quite bluntly, stating, "I see, like, all these

assholes out there that get pregnant and have these kids that they can't take care or don't take care of or don't want. . . ya know, I just, I just feel pure disgust."

Notably, the participants were not angered randomly by the fact that other women had healthy children, but other children were sometimes vivid reminders of the missing child in their own lives . One participant explained,

My sister had just had a baby a few weeks before my child was due, so I came home without a baby, and she had a baby, but she was my sister, so of course, I can forgive her for that.

The presence of other children did spark re-emergence of grief at times. One mother explained, "I was at a niece's party and, ya know, I was like claustrophobic, I was freaking out, I couldn't be around any of [the children]." Likewise, another stated,

One of my friends had a baby. . . around the same time as the due date of that baby that I lost, and, um, almost every time I see her daughter, I get all teary because, ya know, I connect her child with the one, the child that I lost.

Participants who lost one twin described the living twin as a "constant reminder" of the baby who died. One mother explained that each milestone triggers remembrance of the lost child explaining, "When he took his first steps, immediately [my husband] and I are both thinking, I wonder if [the other child] would have done the same thing." Another mother said, "[This baby] deserves everybody in the world to be singing *Happy Birthday*, and all I can do is think 'I should be singing *Happy Birthday* to two children', and it's really hard."

Mothers in the study noted that the pain of separation re-emerges as a result of the careless words of others. For example, one mother recalled, "I ran into other people a year and a half later who said, 'Didn't you have twins?' . . . It always makes me cry."

Likewise, another said, “I’m still having people ask me how the, my baby is, which I don’t have.” One mother recalled overhearing a conversation in which someone mentioned that a person had

“the requisite one child,” and said. . . “ you have no idea why she has one child! You don’t know if that’s a choice she made or if that’s all she could manage!” It was so insensitive. . . just little incidents like that would pop up and then it hits you.

The women learned to respond to others by changing the subject, or by not mentioning the loss.

Perhaps most disturbing to the participants were moments when they felt that the re-emergence of their grief was unpredictable. One mother expressed bewilderment with her own responses to the comments of others, saying, “Some days they can say one thing and it would be fine, they could say the same thing a day later and it, ya know, strikes me very harshly, so I mean that’s unpredictable (laughs).” Another mother recalled being surprised by her own public grief reaction:

We had, like, over \$300 worth of baby clothes. . . so I took everything back. . . I didn’t think it was big deal, I remember. . . as the girl was scanning each thing back in. . . I had a total breakdown in the middle of [the store]. . . it was horrible.

Another mother explained that for her, the grief re-emerges unbidden during quiet times:

“I do long drives 3 days a week, and on those hour drives, I mean, that’s pretty much what I think about, ya know, and I have always, like I’m bawling. . . and at night, a little bit.”

The women described many ways in which they dealt with the longing that was left behind after the loss occurred. Some women reconciled the loss by maintaining an ongoing relationship with their dead children, and were grateful for the lives they had

lived, regardless of gestational age. One mother, who experienced early pregnancy loss noted, “I need to have something that I can remember her by. . . it’s not important to anybody else in the world. . . for me, that child still exists.” Similarly, a participant who experienced a full-term loss said, “He’s with me, ya know. . . everybody else can forget about him, his Mommy never will. . .” And another mother described keeping her daughter’s memory alive by reaching out to help others:

Keeping active and keeping her memory alive. . . the more things I can do, that I should have been doing for her, ya know, I can’t put bows in her hair, but I can arrange [a remembrance ceremony], ya know, I can’t write notes to her teachers, but I can write a letter to the newspaper if something is wrong. . .

Despite creating ways to memorialize their children, the mothers in this study explained that believing that their babies were safe helped them to “let go” of the pain and make a new space for the deceased child in their lives and in the lives of others. One mother described this ongoing presence within the family by saying, “We [tell our other children] one of your sisters is an angel and the other one is with us.” Another mother envisioned the lost child as a protective spirit who had an ongoing role in the family. She said, “He did things so quickly that we always felt he had [his brother’s] spirit in him, and even talked to him about it, ya know, ‘We just know your brother is with you.’” Statements such as these reflected that the participants had reached a point at which they had dealt with the devastation of the loss, internalized their dead family member as a part of themselves, and were able to go on with their lives. Their lives now included both the continuing presence of the baby in their lives and the acceptance that aspects of the pain and loss would always be with them. In order to be able to live with the loss, the women

struggled to make sense of their pain, marking the onset of the next subprocess, *making sense*.

Making Sense

In the subprocess *making sense*, the women moved beyond the medical explanations of their losses and tried to discern the meaning of the loss in their own lives. To try to make sense of the loss, the women frequently turned to faith to explain where reason failed. Some of the women turned to faith and others took part in religious rituals. One mother stated, “Faith definitely helped me. . . I rely on faith for pretty much everything.” Another mother explained the comfort she felt in her darkest moments: “I just feel like. . . God’s just kinda saying, ‘I’m going to take care of you,’ ya know?” Likewise, another noted, “I feel like the Lord is in control, He gives and He takes away.”

Some women discussed religious rituals as a way of coming to terms with the loss. One participant recalled, “I went [to a mikvah] to kinda purify myself and ya know. . . just to say a prayer.” Another took comfort in, as she said, “lighting a candle or having a mass. . .” Faith and religious rituals provided the mothers with a way to place their loss within the greater meaning of human existence.

The women had moved beyond rational explanations of the loss and were primarily concerned with reconciling their feelings of helplessness and the meaninglessness of their suffering. Some of the women formed meaning in their suffering through the belief that there was an unknowable reason for the loss. One mother stated, “I really spent a lot of time finding meaning in it.” And another stated, “I believe

that everything happens for a reason and you may not ever know why.” Likewise, another said, “I knew everything was for a reason.”

Some of the women explained that the reason for the loss was to make a metaphysical space for a subsequent child. As an example, one mother explained,

I was nursing and I looked down at him and it’s just like it made sense, like, if I had had (name), I wouldn’t have had [my younger son]. I would have been in a different place and a different time and I kept trying to think back then, “Oh, everything happens for a reason,” and it sounded like such a tacky cliché, but when I had [my son], it was just like, “Ooooh. . . now this makes sense.”

Another noted, “[My younger child] was meant to be my daughter, so I had to go through everything I had to go through because she was meant to be mine.”

The women reached a point at which they were able to let go of the burdensome pain and to find meaning in their suffering. Construction of the meaning of the loss was an ongoing process, which changed as new life circumstances arose. The women’s experiences of loss and suffering served to transform the mothers’ sense of themselves and their worldview. This sense of continuous change and *becoming* is reflected in statements such as, “I’ll never be the same,” “I’m never going to be the same,” and “Without a doubt, I’m a different person.” Others stated, “I look differently at life,” and another said, “I would love to be that [person] again, but it doesn’t matter at this point.” This shift in the participants’ worldviews and the ongoing impact of the loss on the women’s lives denoted the shift into the final subprocess, *becoming*.

Becoming

Becoming is a process that the participants described as a change from one form of being to another. In this study, the women described feeling more compassionate,

more loving, and more appreciative of the people and relationships they had. In some cases, becoming involved positive changes in interpersonal relationships, especially with the women's partners. Thus, becoming was a transformation of their entire worldview, and involved greater self-awareness and understanding of the fragility of life, which they did not have prior to their own losses.

The participants stated they had a new understanding of the pregnancy loss experience than they had prior to their own losses. One mother explained, "I always thought, well, ya just get over it," but following her own loss, she realized, . . . "you never get over it." Another conveyed the same heightened awareness of the grief realted to pregnancy loss, "Now when someone loses a baby, I very much understand that," and another said of her experience that it "made me more understanding to just anyone in how they handle a pregnancy, or a loss of any kind." With these new insights, the women felt better prepared to reach out to others who experienced a loss.

The women reported becoming "more sympathetic," "more sensitive," and "more compassion[ate]." For example, one participant recalled reaching out to a man following the loss of his granddaughter saying, "I wrote to [him] right away because I wanted him to know that I understood his grief." Another expressed similar sentiments, stating, "I have many friends who miscarried, and I always send a card now, just, 'Thinking of you,' or 'I'll keep you in my prayers.'" Others also felt better prepared be supportive, "[the loss] was really a lesson for me in dealing with other people." Likewise, another participant mentioned, "If somebody, ya know, came up to me upset that she had a

miscarriage, I would be, um, much more able to help her.” Another mother stated, “I was able to provide support for other women in those situations.”

In addition to becoming more sensitive to the suffering of others, the participants also noted greater sensitivity to the fragility of the human condition, stating, “If I can get philosophical for a minute. . . I’m so aware of how fragile life is.” This newfound understanding was described by one mother who said,

You think, ya know, getting pregnant’s easy. Ya know, you get pregnant, you have kids, that’s how people live. . . [After the miscarriage], it was like maybe it’s not so easy and maybe I need to think about this as more of a gift and not just an expectation, so I think that really shifted for me.

Another mother stated, “I focused more on being a better mother and a better person and just enjoying the time that I have because I know in a second it could be over.” The participants explained that reflections such as these fostered a deep appreciation for their children, as evidenced in statements like, “I have a deep sense of gratitude for the people in my life,” “I appreciate my children more,” “You try to cherish [your children] more, spend more time [with them],” and “I’m thankful every day that I have them, every day that I can touch them, and speak to them.”

Some of the participants related a deepened gratitude, specifically to God, for their living children, which can be described as religious or spiritual growth. One participant noted, “My faith has grown so much stronger.” Another one said, “I’ve [changed], I think, spiritually.” Similar feelings were evident in statements such as, “What a blessing these kids are,” and “I thank God I have [my daughter], like I’d never been so grateful for her in my whole life.” Another participant explained, “We cherish those little moments where all the kids pile up on the bed, and the dog, we really look at

those things as gifts.” One mother said that her loss “probably intensified” her relationship with her other children, and another stated, “My relationship with the kids, it’s gotten so much stronger.”

The women developed stronger emotional bonds with others as well, which resulted primarily from the support they received. One mother explained,

[A relative] who I really didn’t like very much. . . happened to call me and we talked about, ya know, miscarrying, and she said she had a number of miscarriages. . . and I remember talking to her about it and just kind of letting it all go. . . I felt much closer to her.

Another participant commented, “My [relationship with] my stepmom has gotten stronger, actually, because she kinda gets it. I’m able to talk to her and she’s very thoughtful about stuff.” One mother noted, “[My sister] was always there for everything. . . so I think that strengthened it even more.” In general, the participants felt closer to those who offered support throughout their bereavement. Specifically, their relationships with their partners were strengthened as a result of working through the loss together.

Several of the participants described a deeper and closer relationship with their partners following the loss, using statements such as, “We definitely felt like it was just kinda pulling us closer together,” and “I think the whole thing brought us closer together emotionally.” This closeness did not occur accidentally; it developed through the couples’ commitment to work through the pain of the loss together. The participants noticed changes in their partners, which deepened their affection.

The participants often felt their partners had the best understanding of what they were going through and that they had been irrevocably changed by the loss. One mother

explained, “When we were in the delivery room. . . he did a 180-degree turn. . . gone was that angry, belligerent person. . . he’s been wonderful.” Another noted, “He was wonderful.” Nine years after her loss, one participant explained, “There are times when we just have to step back and say, ‘Wow, look at what we’ve come from and what we’ve been through, and ya know, things happen and they’re not as important as we’re here together.’”

Such statements indicated an irreversible re-organization of the women’s priorities. This change was described with statements such as, “It was a blessing in disguise, my priorities have changed,” and “It’s made me appreciate certain things in life and it sounds so trite and so ridiculous. . . but I do, because, you had the worst that can happen to you and nothing else seems that important.” Another participant noted, “I have less tolerance for the minutia,” and another added, “I don’t let the little stuff get to me anymore, and I mean , in a big way, I mean it’s just whatever the problem is, ya know, this isn’t a problem. Losing your baby, that’s a problem.” Others made similar statements:

I don’t care anymore. . . I just feel like I was so worried about [work] and what I should have been worried about was the babies, and I, I never really thought anything could happen to them. . . I was worried about these other things—now, somehow it just doesn’t seem, it, it’s not important to me.

Another mother summed up her feelings, stating, “People at work complain, ‘Oh, yeah, ya know, the boss said this to me.’ Well, I don’t care, my daughter died, ya know?”

The process of maternal perinatal bereavement discovered through this grounded theory study began with Experiencing the pregnancy and ended in an ongoing process of Transcending the suffering. The mothers moved through the categories in temporal

order, except for the category Transcending the suffering. The category Transcending the suffering has three fluid properties, which are longing, making sense, and becoming. The categories and their subcategories are depicted in Table 2.

Table 2. Taxonomy of the Maternal Perinatal Bereavement Theory: Pushing On

Core category: Pushing on	
Stages	Subprocesses
Experiencing the pregnancy	Finding out about the pregnancy
	Developing a relationship
	Mothering
Losing the baby	Interpreting signs
	Getting the news
	Feeling numb
	Making painful decisions
Bearing the burden	Comforting others
	Apprehending the loss
	Succumbing to grief
	Searching for answers
Working through the pain	Feeling frustrated
	Letting it go
	Engaging again
	Seeking help
	Reflecting

Table 2 (continued)

Core category: Pushing on	
Stages	Subprocesses
Transcending the suffering	Longing
	Making sense
	Becoming

Assessing Veracity

According to Glaser and Strauss (1967), when a grounded theory is generated from data obtained from those who have lived an experience, the researcher can feel confident “in his bones” (p. 225) that the results are credible. Glaser and Strauss developed systematic criteria for judging the veracity of a grounded theory. The theory that was discovered through this study was evaluated using these four criteria: fit, work, relevance, and modifiability (Glaser, 1978, 1992, 1998; Glaser & Strauss, 1967).

Fit

By fit, Glaser and Strauss (1967) meant that the theory must “fit the situation being researched” and “that the categories must be readily (not forcibly) applicable to and indicated by the data under study (p. 3).” In this study of maternal perinatal bereavement, the data gathered from the interviews were analyzed through constant comparison. Development of the processes and subprocesses discovered in this study were derived from the stories of women who had experienced maternal perinatal bereavement,

ensuring that the theory conforms to the experience as it was described by the participants. The theory satisfies the criterion of fit and its reflection of the process of maternal perinatal bereavement is assured.

Work

The second criterion, work, indicates that the theory “must be meaningfully relevant to and able to explain the behavior under study” (Glaser & Strauss, 1967, p. 3). The theory discovered in this study explicates the process of maternal perinatal bereavement in a way that has not been presented previously. The new insights offered into the process make it possible to explain the consequences of pregnancy loss and the reactions of bereaved mothers. This information is particularly helpful for health care providers because it “imbues thought” (B. Glaser, personal communication, June 24, 2009), meaning that it influences the approaches they may take when working with bereaved women.

The theory discovered in this study is useful for women who have experienced pregnancy loss, as it will help them to understand their own feelings and ease their feelings of isolation. It will help women who are in the early stages of the process gain an understanding of what lies ahead in the process. The theory is useful for the spouses and family members of bereaved women because it provides a framework for maternal perinatal bereavement and validates the changes women experience after a loss.

Relevance

Relevance indicates that the theory explains “how what is going on is continually resolved” (Glaser, 1998, p. 236). In this study, it was determined that the gnawing absence of the child in the women’s lives became less intense over times, but periods of re-grieving occurred that often surprised the mothers. The women were able to work through the initial overwhelming pain of the loss and the subsequent waves of grief by the repetitive process of pushing on, which was identified as the core category. The key processes of maternal perinatal bereavement were discovered through the grounded theory process.

Modifiability

Modifiability of the theory is the next criterion that must be met. It indicates that the theoretical concepts discovered in the study can be readily modified for use in other substantive areas. The core category, pushing on, could be easily related to numerous life situations in which one must muster strength to go on despite hardship such as coping with the aftermath of an unwanted divorce or loss of a limb. The ability of others to consider the applicability of the core variable in other substantive areas is referred to by Glaser as “the reversibility of the interchangeability of indices” (B. Glaser, personal communication, June 24, 2009). Such applicability allows people to use the theory meaningfully and adds credibility to the theory.

Referring more generally to the “interrelated jobs of theory,” Glaser and Strauss (1967, p. 3) noted that all theories serve five purposes: (a) to predict and explain behavior, (b) to further advance theory in a field, (c) to be useful in practice, (d) to

provide perspective, and (e) to guide future research. Each of these criteria is addressed separately.

The substantive theory presented in this chapter satisfies the first purpose of a theory in that it *predicts* the path women are likely to experience in response to the event of pregnancy loss and it *explains* women's reactions to loss. It *advances theory* in the substantive area by offering an empirically derived theory that can guide practice. The theory is *useful in practice* because it can serve as a framework for nurses and others who must deliver the news of pregnancy loss and support women who struggle with grieving. This means that, with their understanding of the sequelae of pregnancy loss, health care providers such as nurses, nurse practitioners, and physicians may approach bereaved women in a more understanding and compassionate manner. Also, health care providers who have an understanding of the process of maternal perinatal bereavement will be better prepared to inform women of what to expect following maternal perinatal loss. The theory is useful to parents whose baby died in utero because it provides perspective and offers an understanding of the process of maternal perinatal bereavement. Its process, as presented in this study, *guides future research* by identifying various dimensions of bereavement that had not been identified previously. The unique contributions of this study and future research avenues will be discussed further in chapter five.

CHAPTER V:

DISCUSSION

The purpose of this chapter is to describe the key findings in the study of maternal perinatal bereavement and to distinguish findings that support previous research from those that are unique to the theory. The storyline, which is a summary of the findings in layman's terms (Glaser & Strauss, 1967), is presented to orient the reader. The ensuing discussion of the findings is organized within the five stages of the "Pushing On" maternal perinatal bereavement theory. The chapter concludes with an overview of the strengths and limitations of the study, applicability of the research in nursing practice, and implications for future research.

Storyline

This study of maternal perinatal bereavement resulted in an empirically derived substantive theory, beginning with a woman becoming pregnant, experiencing the pregnancy and the death of the anticipated baby, and culminating in an ongoing process of transcendence. The core category, pushing on, explains how the women dealt with receiving the news of the loss, how they carried on despite the intense emotional pain that followed the loss, and how they coped with episodes of re-grieving.

The women's stories of loss began with their expressing thoughts about when they found out about the pregnancy, began to personalize the expected babies, and envisioned how their lives and the lives of their loved ones would change after the birth

of the child. Although the participants were not completely naïve to the possibility of pregnancy loss, they were shocked when confronted with the news that their babies had died. They experienced emotional numbness and reported a sense of being detached from everyday life. Slowly, they began to comprehend how the loss would affect numerous dimensions of their lives, including their partner's and children's lives, and its impact on their day-to-day lives. As their awareness grew, so did the emotional burden. The women were burdened by the hurtful responses of others and by the expectation that they had to support their loved ones through their grief. They were distressed at being confronted by the unpredictability of life and began to fear the possibilities of additional losses.

Eventually, the women could no longer bear the weight of the grief and surrendered to the pain. In this state, they were barely able to function in their usual roles and experienced deep sadness, crying, and emotional pain. This dark period was described as "awful," but in time, the women were drawn out of their sadness by their responsibilities to others. They recognized the need to "get back to life," care for their other children, and return to work. They made a conscious effort to engage in life again, and work through the pain. They spent time reflecting on their loss and talking to others, especially those who had also experienced a perinatal loss. These efforts helped to reduce the isolation they felt and helped them to find meaning in the loss. Many of the participants described the loss as a life-altering experience which caused them to become more appreciative of others, more loving, more tolerant, and more forgiving. Once the women were able to transcend the loss, they experienced life in a new way, with the loss permanently woven into the tapestry of their lives. The process of maternal perinatal

bereavement, as discovered in this study, had a beginning and a mid-point, but it did not end. Rather, the women continued to carry the baby's absence and it influenced their personal becoming in an ongoing way.

Core Category

The core category, Pushing On, denotes that the women had to actively work to push through the pain of the loss and to re-engage in life. The women's ability to push on waxed and waned throughout the process, and they experienced the re-emergence of grief, sometimes randomly, but they repeatedly mustered the energy to push on. No studies were identified that offered this description of how women worked through the process of maternal perinatal bereavement. Other researchers have identified that recovering from bereavement is an active process, which involves engagement and effort (Freud, 1957; Hogan, Morse, & Tasón, 1996; Hogan & Schmidt, 2002; Worden, 1983, 1991, 2002). Other insights into the experience were generated from the data and are addressed individually in the following sections, by category.

Stages

Experiencing the Pregnancy

In terms of experiencing the pregnancy, one of the most unexpected concepts discovered in the data was how mothers formed prenatal relationships with their unborn children. The mothers began develop a relationship with their babies when they made the choice to accept the pregnancy, regardless of whether the pregnancy was planned or unplanned. The mothers described developing a bond with their babies through making a place for the baby in the family, naming the baby, and assigning personality traits. Earlier

work on maternal bonding suggested that maternal attachment did not take place until quickening (Rubin, 1984), which typically occurs at approximately 16 weeks of gestation. Previous research indicated that technological advances such as ultrasound foster earlier attachment (Black, 1992; Righetti et al., 2005; Robinson et al., 1999), but the results of this study support the conclusion that bonding begins with acceptance of the pregnancy and that milestones such as hearing the baby's heartbeat, seeing ultrasound images, and feeling the baby's movements served to deepen a relationship that had already begun.

Because attachment is considered a necessary condition for a grief reaction to occur (Bowlby, 1969, 1973), it is likely that Rubin's (1984) theory, which indicated that maternal attachment did not begin until quickening, has fueled the misconception by health care professionals and the public that early pregnancy loss would not result in a bereavement process. Despite numerous reports of women grieving a perinatal loss (Abboud & Liamputtong, 2005; Adolfsson et al., 2004; Friedman & Gath, 1989; Van & Meleis, 2003; Wheeler & Austin, 2001), the relationship between attachment and perinatal bereavement had not been studied systematically. The findings of this study extend the previous understandings of prenatal maternal attachment by clarifying that although quickening and technological advances can deepen the relationship between a mother and her baby, the relationship actually begins when the mother becomes aware of the pregnancy. The mother then begins taking steps to incorporate the baby into her own life and the lives of her partner and other children. As a mother forms an emotional

attachment to her baby, she begins mothering the baby in utero by making decisions about the best way to care for and protect him or her.

The women in this study discussed the steps they had taken, such as seeking prenatal medical care, counting the baby's kicks, and taking prenatal vitamins. In these ways, the women worked to monitor their child's physical activity and follow prescribed care guidelines to provide the child with a good intrauterine life. A literature search for studies on prenatal mothering yielded no results. Rather, the extant literature addressed the concepts of how women transition into motherhood (Sawyer, 1999) and maternal role attainment (Cooke, Schmied, & Sheehan, 2007; Mercer, Kay, & Tomlinson, 1986; Rubin, 1984) after delivery of a live baby.

Attention has been given to "becoming a mother" of a live baby, a concept which was discovered through grounded theory research (Barclay, Everitt, Rogan, Schmied, & Wyllie, 1997; Rogan, Schmied, Barclay, Everitt, & Wyllie, 1997). Mercer (2004) recommended that use of the phrase "maternal role attainment" be replaced with the term "becoming a mother," which has garnered support (Deskin, 2005; Fowles & Horowitz, 2006). This new understanding of how women transition into motherhood is an important step forward in gaining an understanding into the life experiences of women.

The process of becoming a mother identified by this study differs from that described by Barclay et al. (1997). According to Barclay et al., the process begins after birth, when the women gradually become aware of the full impact of being completely responsible for the baby. The results of the pushing on maternal perinatal bereavement theory indicate that the process of becoming a mother begins when women first learn

they are pregnant. The mothers discussed lifestyle changes such as ceasing to drink alcohol, taking prenatal medication, and receiving routine prenatal care. During this time early in pregnancy, they begin bonding with their unborn children. This finding helps explain previous reports indicating that gestational age did not influence perinatal grief (Hutti, 1992; Swanson et al., 2007), because a relationship had already begun between mother and child.

As with most relationships, the women's attachment and affection for their children grew over time as the women learned more about the child through hearing the heartbeat, ultrasound, and feeling fetal movement. In this study, women who experienced losses after 16 weeks gestation described deeper grief that was more difficult to transcend. Thus, the results of this study extend previous findings regarding maternal attachment and the initiation of mothering behaviors. The mothers' actions in ensuring the health and well-being of their babies indicated that they anticipated a live birth and believed that they could influence the outcomes of their pregnancies through their actions. They persisted in this belief until they were faced with losing the baby.

Losing the Baby

The stage, Losing the baby includes the processes whereby the mothers recognize that the baby's life could be in jeopardy, extends through the death notification, and ends with the mothers needing to make painful decisions regarding aftercare of the babies' remains. Initially, the women struggled to grasp the seriousness of the events as these unfolded. The women's ability to differentiate signs that their pregnancies were progressing well from signs of possible problems was described by Hutti (1986, 1992).

This was not the case for all of the women in this study. Although some did note signs of trouble and seek help, others were surprised by the loss.

An aspect captured uniquely in this study was that of the women interpreting the signs of their losses, in part, by consulting others. Often, the women first discussed their suspicions with someone close to them, such as a spouse, and then consulted a health care provider. The reactions of others, including health care providers, gave the women clues about the seriousness of their symptoms. When the women decided to seek care, they already had a significant amount of information about the possibility of a loss and decided to seek care to alleviate or confirm their worst fears. Throughout the process, the women continued to maintain hope until faced directly with the news of the baby's death. Kavanaugh and Hershberger (2005) reported similar findings, stating, "even those parents who were told of their baby's deaths in utero were hoping that there would be a miracle" (p. 599).

When the women discussed getting the news of the baby's death, they recalled the exact words they heard and the intonation of the words. They interpreted the delivery of the information as either cold or compassionate. Their meeting with a health care professional was a pivotal moment, and the memory remained with the mothers long after the loss. Delivery of this important, albeit terrible news, has garnered some attention in the perinatal loss literature (Kavanaugh & Paton, 2001; Romm, 2002), but is typically couched within the larger context of communication. The women in this study stated they were better able to understand direct information such as, "She's dead," rather than vague

innuendos such as, “There’s no heartbeat,” to which one participant replied, “What does that mean?”

After receiving news of the loss, the women reported numbness, which is characteristic of suffering the loss of a loved one (Hogan & DeSantis, 1992, 1996; Hogan, Morse, & Tasón, 1996; Lindemann, 1994; Ritsher & Neugebauer, 2002). Perinatal researchers (Rillstone & Hutchinson, 2001) identified numbness and shock as aspects of the emotional suffering. The participants in this study recalled that making painful decisions through the numbness was a difficult aspect of the loss. Others have identified that bereaved mothers are overwhelmed by the loss and often have difficulty making decisions.

Säflund et al. (2004) recommended that health care providers give women “firm but kind direction,” which was a guidance echoed by others (Kavanaugh & Moro, 2006; McCreight, 2008). Kavanaugh and Hershberger (2005) pointed out the importance of receiving accurate information about burial options, including the cost or availability of financial assistance. It is apparent the health care provider’s skill in delivering the news of the baby’s death and ability to support bereaved mothers afterward is crucial for ensuring that further emotional burden is not placed on women in the immediate post loss period.

Bearing the Burden

The third stage, Bearing the burden, began after the loss when the participants shared the news of the loss and found that they were called upon to support others, including family members and friends. The importance of giving and receiving social

support for bereaved individuals who have lost a loved one with whom they shared a life is well documented. Van and Meleis (2003) identified the need to support others was often viewed by bereaved mothers as causing them additional emotional distress. The need to support others has been well documented in national and international bereavement studies (Hogan et al., 1996; Hogan, Greenfield, & Schmidt, 2001; Hogan & Schmidt, 2002; Kaunonen, Tarkka, Hautamäki, & Paunonen, 2000; Kaunonen, Tarkka, Paunonen, & Laippala, 1999).

In contrast to their need to provide support to others, most of the women in this study felt abandoned after the loss and isolated from others. Even those who did feel well supported by family members conceded that their emotional suffering continued long after others had moved on. In other studies of perinatal loss, women typically reported feeling poorly supported (Hale, 2007; Hsu et al., 2004; Morrissey, 2007; Sansoni & Giaquinto, 2001; Van & Meleis, 2003). A social aspect of perinatal loss discussed by the women was a lack of recognition of their loss. They noted that discussing the loss was seemingly taboo, and because most people had not even known about the pregnancy, the mothers felt they could not discuss the loss. This inability to talk about what was very much on their minds was particularly distressing when the women returned to work and had to “pretend everything was ok.” This common feature of pregnancy loss led Doka (2002) to identify miscarriage as a form of disenfranchised grief.

The women in this study reported sadness, crying, inability to sleep, lethargy, anger, self-blame, questioning why the loss occurred, and emotional devastation and detachment, which are consistent with the findings of other perinatal loss studies

(Friedman & Gath, 1989; Harvey et al., 2001; Hsu et al., 2004; Janssen et al., 1996; Wheeler & Austin, 2001). Enhanced fears of additional losses were reported in this study. The women described feeling fearful that their living children might die. They feared the possibility of a subsequent perinatal death, which has been reported in other studies of perinatal loss (Barr, 2006; Côté-Arsenault & Dombeck, 2001). Côté-Arsenault, Donato, and Earl (2006) noted that pregnancy after loss was fraught with “omnipresent worry and anxiety” (p. 356), which, in this study, was considered part of the burden of perinatal loss.

The emotional suffering that ensued after the loss caused the mothers to question why this fate had befallen them, which is common following loss or trauma (Bowlby, 1973; Hogan et al., 1996; Hsu et al., 2004; Kalischuk & Hayes, 2003; Lindemann, 1994; Parkes, 1998; Tedeschi, Park, & Calhoun, 1998). Unable to find answers, the women became angry, which is another common reaction to loss (Bowlby, 1973; Hogan et al., 1996; Kalischuk & Hayes, 2003; Lindemann, 1994; Parkes, 1998; Wollheim, 1971; Worden, 2002). After a period of holding their emotions in check, the women in this study began to release their anger by lashing out at others, which was actually a sign that they were gaining the emotional strength needed to work through the pain of the loss. Sefton (2007) noted similarly that among adolescents who had experienced pregnancy loss, “conflicts and anger toward those around them were common, often involving increased arguing with loved ones or assigning blame” (p. 17). At a certain point in the bereavement process, the women recognized the need to let go of some of their anger, and soon began the process of working through the pain.

Working Through the Pain

The fourth stage, Working through the pain occurred when the women began to invest their emotional energy in healing instead of suffering, they discussed letting go of the frustration and pain they felt as a result of the unkind words or inappropriate responses of others, a finding which has not been noted in other studies of perinatal bereavement. Likewise, the subprocess of letting go has not been previously discussed in bereavement literature, but is intuitively logical as a first step in overcoming anger and blame. When the women were able to let go of the anger and blame they had been harboring, they were ready to begin the process of engaging again in life. Despite a willingness to re-engage in the life they had known, they quickly recognized that they no longer saw life in the same way and craved the support of others in making this invisible transition. They sought help from Web sites, books, and other women, which has been discussed by other researchers (Adolfsson et al., 2004; Côté-Arsenault & Freije, 2004; Hutti, 1992).

Reading books and Web sites about loss and talking with others helped alleviate the isolation the mothers felt. As they took in the experiences and words of others, they compared these to their own experiences. This period of reflection was an important dimension of the bereavement process; it allowed the women to take in the loss and assess their own responses. Self-monitoring has not gained attention in the perinatal loss literature per se, but some recommendations do exist on when to seek professional help for grief (Capitulo, 2004; Pector & Smith-Levitin, 2002). Capitulo (2004) specifically differentiated between 'normal' and 'complicated' grief following pregnancy loss.

Complicated grief reactions include inability to perform normal roles, the manifestation of severe depression or suicidal ideations. According to Capitolo, the primary treatment for complicated grief is allowing the bereaved individual to repeatedly tell the story of the loss. In this study, the women described a period of time during which they were unable to perform their normal activities, but none described feeling severe and persistent depression or suicidal thoughts. Informal and formal networks allowed the women to tell their stories of the loss and connect with others who had similar experiences.

Supplementary to reflecting and self-monitoring, the mothers in the study discussed the role of mementos in validating the life that was lost and allowing the mothers to maintain some connection with their babies. The importance of these powerful, tangible reminders of the baby that were created by nursing staff has been addressed in the literature (Kavanaugh & Moro, 2006; McCreight, 2008). A contribution unique to this study is the insight it offers in helping situate previous findings regarding the importance of mementos within the larger context of reflection.

Knowing how the mementos fit into the larger picture can help establish support for healing interventions such as the creation of mementos. Kavanaugh and Moro (2006) specifically recommended giving parents the items that had come in contact with their babies such as blankets and caps, taking photos, and making casts of the baby's hands and feet. The participants who received such mementos in this study reported they were cherished reminders of their lost children. They noted that the time spent reflecting on the loss helped them to find meaning in their suffering and to eventually transcend the pain of the loss.

Transcending the suffering

The women described continuing to miss and long for the baby throughout their lives, but especially on significant dates such as Mothers' Day, the baby's due date, death date, and around holidays. In the last stage of the theory, the women described an ongoing sense of becoming, which in this study was viewed as a change from one form of being to another. The women discussed transcending the pain but continuing to miss and long for the lost child. The integral elements of missing and longing as a part of the perinatal bereavement process have been described by qualitative researchers (Hsu et al., 2004; Wojnar, 2007). Interestingly, in studies of the deaths of adolescent siblings (Hogan & DeSantis, 1992, 1996) and spouses (Hogan & DeSantis, 1992, 1996; Hogan & Schmidt, 2002; Parkes, 1998) with whom participants had shared a life, participants discussed continuing to miss and love the deceased loved one.

As the women in the study began to transcend their suffering, they were able to find meaning in the loss. They believed that there was a reason for their suffering, even if they could not verbalize that explanation. Some of the women believed that God had a plan for them or for their babies, and were comforted by the idea of a higher purpose for their pain. Kavanagh and Hershberger (2005) found a similar process, "making sense of the loss," in which bereaved women "questioned the death from a philosophical or spiritual perspective and explained it within a religious context" (p. 602). Searching for meaning in perinatal loss has been well described in other studies of perinatal loss (Clower, 2003; Sefton, 2007; St. John et al., 2006). Examining one's suffering and

finding meaning in the suffering have been described as an “existential experience” (Hogan & DeSantis, 1996, p. 177).

According to the Pushing On maternal perinatal bereavement theory, mothers searched for meaning and came to recognize that they had been changed by the death and bereavement they had experienced. The subcategory that included the women’s descriptions of this process is *becoming*. No studies of perinatal loss were identified that specifically addressed becoming. However, one nursing theory, The Theory of Human Becoming (Parse, 1998), addressed becoming as “ongoing mutual participation with the universe” (p. 31). In contrast, in this study, becoming was viewed as a change in the women’s worldview that specifically resulted from the bereavement process.

The women stated that the changes they experienced were, for the most part, positive. The mothers reported feeling more tolerant, more compassionate, and more appreciative, which are dimensions of growth that have been empirically identified (Hogan, Morse, & Tasón, 1996; Hogan, Worden & Schmidt, 2004). New dimensions of the experience of becoming as it relates to perinatal bereavement have been discovered in this study, and include gaining perspective and emotional strength, and maturing as a result of the loss. Although these specific dimensions of perinatal bereavement had not been previously identified, pregnancy loss has been cited as a transformative experience (St. John et al., 2006). In studies of other forms of loss, becoming has been reported as an outcome of bereavement (Hogan & DeSantis, 1992, 1996; Hogan et al., 2001; Hogan et al., 1996; Hogan & Schmidt, 2002; Worden, 2002). Becoming in the form of personal

growth has also been confirmed as a dimension of pregnancy loss in national and international studies (Clower, 2003; Sansoni & Giaquinto, 2001).

Unique Findings

Results of the study revealed several new insights into the experience of perinatal bereavement. For instance, the participants in this study reported that an emotional attachment began to form with their unborn children as soon as they accepted the pregnancy. The finding supports Bowlby's (1969; 1973) claim that attachment is a prerequisite for a grief response, but refutes Rubin's (1986) assertion that prenatal attachment begins with quickening at 16 weeks gestation. In fact, Rubin's work may have fueled societal views that early pregnancy loss would not result in a grief response because no attachment to the expected child would have been established. The results of this study indicate that prenatal attachment not only begins with acceptance of the pregnancy, but continues to deepen throughout the pregnancy as the mother comes to know her child through ultrasound, hearing the baby's heartbeat, and later, feeling the baby move. Either technology has changed women's experiences of maternal attachment since Rubin's theory was developed, or Rubin's work did not explicate the process accurately because it was rationally derived. The findings of this study support other research reports of grief responses to early pregnancy loss, but because the relationship grows over time during the pregnancy, it also supports literature that later pregnancy loss is more difficult to transcend.

Another unique finding in this study was that when women interpreted the signs of loss, they often turned to a loved one to help them determine the severity of the signals

they received. Hutti, (1992) noted that women monitored their pregnancies, interpreting both positive signs and signs of potential problems. But, the intricacies of how women picked up on cues, consulted with someone else and then made decisions regarding when to seek care have not been previously discovered. Additionally, the way women interpreted the actions of health care providers and concluded that there was a problem had not previously been addressed in the extant literature.

The women in this study discussed interpreting the signs of trouble while simultaneously maintaining hope. But, upon getting the news of the loss, the women reported feeling emotionally numb, which has not been addressed in the perinatal loss literature. In fact, most of the literature focuses specifically on women's emotional responses to loss. The discovery of a brief period of emotional numbness is especially important because discussed self-monitoring and as one mother noted, "I felt nothing. . .and I didn't know what was wrong with me."

Another dimension of the experience of perinatal loss that has been clarified as a result of this study is that women tend to feel more anxious and fearful in subsequent pregnancies. In this study, however, women reported fearfulness that was not restricted to a subsequent pregnancy. Feelings of fearfulness in regard to viability were reported by many of the women in this study as a dimension of bearing the burden of the loss. The women expressed apprehension about losing their marriages through divorce or death, fear of losing their parents or other loved ones, and even fear of their own death. Notably, this fearfulness was sometimes exhibited as hypervigilance during subsequent

pregnancies, and during times when their other children were ill. The findings of this study, therefore, offer new insights into the emotional burden of pregnancy loss.

Another unique contribution of this study is the explanation of how women were able to move beyond some of the pain of the loss. Through the process of ‘letting go’ women were able to forgive themselves and others and let go of some of the blame and anger they experienced following the loss. Ultimately, the women were able to transcend the pain of the loss through both forgiveness and reflection. The discovery of the process of reflection explains why mementos such as handprints, footprints, and photos that have been recommended in the literature are helpful. The mementos provided tangible evidence of the loss and validated the mother’s pain, and helped the women to move towards the positive outcomes of grief, such as emotional strength, maturity and deepened faith, that were discovered in this study

Strengths and Limitations

One of the strengths of this study is that a substantive theory of bereavement was discovered and consistent with extant grief concepts, such as the Grounded Theory titled, Experiential Theory of Grief (Hogan et al., 1996). The Pushing On Theory described in this dissertation includes new concepts that have not been reported in the literature. For example, findings showed that mothers whose loss had occurred between 12 weeks and 28 years prior to the interview had similar descriptions of their grieving process and the ongoing nature of continuing to be regretful that their baby had died. Mothers described the longing that resulted from the loss of their babies, regardless of the gestational age of the child at the time of loss.

Although the results of this study provided many new insights and help to situate earlier research within the broader process of maternal perinatal bereavement, several limitations were noted. The theory discovered in this study was derived from a relatively homogenous group of women of similar cultural backgrounds. This characteristic of the study strengthens some findings but leaves gaps in the knowledge of the degree to which culture plays a role in the perinatal bereavement process. Another limitation of the study is that the majority of participants were married at the time of loss, which likely influenced their experiences of the bereavement process, especially because the women reported that their partners best understood their pain. Whether the process would be the same for unpartnered women is uncertain.

Implications for Nursing Practice and Nursing Education

The findings of this study have implications for the practice of nursing. The professional mandate for evidence-based practice is facilitated by nurse researchers who generate data-based theories from which to conduct research-based practice. This study specifies several ways in which the care of bereaved women can be improved. First, the pushing on maternal perinatal bereavement theory informs the practice for nurses who work with bereaved mothers by helping them to conceptualize the perinatal bereavement process. Conceptualization allows nurses to understand the process and incorporate that understanding into individualized plans of care.

Nurses could learn from mothers to personalize the loss. The mothers in this study used the term baby when speaking of their losses. They never used medical words such as fetus, ovum, or abortion. One very simple change in practice would be to use the words

mothers use when discussing their losses, and say the word baby instead of using medical jargon. If the baby was given a name, it is also appropriate to use the baby's name to show respect. This simple change could convey compassion and understanding.

Because mementos were repeatedly cited as helpful for the mothers to use during the periods of reflection, the practice of creating memory boxes, taking photos, and making casts of the baby's hands or feet should be standard. For mothers who experienced early losses, validation of the pregnancy and the loss is important. Simple measures can be taken in women's health clinics to meet this need, such as giving the mothers a copy of laboratory results, which confirmed the pregnancy, ultrasound photos, or recordings of the baby's heartbeat.

In order to implement changes in practice, education is needed, especially in regard to the process of maternal perinatal bereavement. Specifically, both student nurses and practicing nurses should be aware of the long-term effects of perinatal loss and the role of the nurse in facilitating healing. The results of this study explain why the interventions recommended in the literature such as appropriate communication and creating mementos are meaningful to bereaved mothers. Because nursing interventions are so crucial to the experience of mothers, nurses must advocate through policy development for the time and training to meet the patients' needs.

The results of the study indicate that nurses play a pivotal role in ensuring the emotional well-being of mothers in the weeks, months, and years following perinatal loss. For example, in addition to the nurses' involvement in creating mementos, the support groups that were discussed by the women were nurse-run. What is not clear from

the literature is the prevalence of nurse-run support groups or the preparation of nurses to run such groups.

Implications for Future Research

The mothers described the baby as someone they came to know and with whom they bonded during the pregnancy. Because the findings of this study challenge previous theoretical descriptions of prenatal attachment, future research could be conducted to further explore the dimensions of prenatal mothering that were discovered in this study. Study of the bereavement process might be extended to include other family members such as expectant fathers, siblings or grandparents.

This research study revealed the process of maternal perinatal bereavement starting with conception, through death and its aftermath. Mothers actively chose to push on despite feeling overwhelmed by grief. It would be worthwhile to study mothers who fail to push on and instead succumbed to remaining stuck in their grief. Because it was determined that the core category, pushing on, enabled the women to move beyond the initial pain of the loss and deal with periods of re-emergence, future research could be conducted to determine the factors that influence the process by which women push on beyond their grief.

Pushing On also allowed the women to move beyond periods of regrieving that occurred under certain circumstances such as the baby's due date, and Mother's Day. Although episodes of regrieving were distressing, the women did not experience the all consuming grief they felt earlier in the process. Rather, episodes of regrieving, were less intense and shorter in duration.

This new knowledge regarding initial reactions to perinatal loss and the nature of the grief throughout women's lives could give way to the development of a new perinatal bereavement instrument. The new instrument could then be validated in a study of maternal bereavement that included a valid and reliable measure of grief, such as the Hogan Grief Reaction Checklist (Hogan, Worden, & Schmidt, 2004). In this way, the essential features of perinatal bereavement could be isolated. Alternately, it could be identified that few differences exist between the loss of an expected child and the loss of an older child.

Once a valid instrument is developed using the data obtained in this study, the findings could be compared with extant perinatal instruments to determine how an empirically developed instrument derived from bereaved mothers' data compares to rationally derived instruments. The new instrument could also be used in a subsequent study to test the theory through structural equation modeling which simultaneously tests multiple pathways.

In summary, the pushing on maternal perinatal bereavement theory is an empirically derived representation of the process that women experience following pregnancy loss. This theory can be used to educate nursing students, practicing nurses, and the general public about perinatal loss and the experience that is often misunderstood and minimized. The theory can be useful in guiding nursing practice toward a more compassionate approach to bereaved mothers, an approach that is grounded in the words of bereaved mothers.

APPENDIX A:
LETTERS OF APPROVAL



OFFICE OF RESEARCH SERVICES

To: Patricia Moyle Wright
From: Maria Landis, Research Compliance Coordinator *ML*
Date: November 30, 2007
Re: IRB Protocol #26-07C
Maternal Perinatal Bereavement

The revised protocol referenced above has been approved for a period of one year.

Any further changes to the protocol must be approved by the IRB administrator prior to instituting them.

Adverse or unexpected events must be reported immediately to the IRB Chair.

If you have any questions, please do not hesitate to contact me.

cc: Margarete Zalon, Ph.D., IRB Chair



INSTITUTIONAL REVIEW BOARD
FOR THE PROTECTION OF HUMAN SUBJECTS

To: Patricia Moyle Wright, Nursing

From: Maria Landis, Research Compliance Coordinator 

Date: November 18, 2008

Re: IRB Protocol #26-07C
Maternal Perinatal Bereavement

I am pleased to advise you that your request for an extension on the above referenced project (approved November 29, 2007) is approved for a period of one year.

Any changes to the protocol must be approved by the IRB prior to instituting them.

Adverse or unexpected events must be reported immediately to the IRB Chair.

If you have any questions, please do not hesitate to contact me.

cc: Margarete Zalon, Ph.D., IRB Chair



Research Services
Institutional Review Board for The Protection of Human Subjects
Lakeside
Lake Shore Campus
6525 N. Sheridan Road | Chicago, Illinois 60626

January 28, 2008

Patricia Moyle Wright

Dear Ms. Wright,

Thank you for submitting the research project entitled: **Maternal Perinatal Bereavement**, for *expedited review* by the Institutional Review Board for the Protection of Human Subjects. After careful examination of the materials you submitted, we have **approved** this project as described for a period of one year. **The IRB has approved the final version of the consent form and enclosed is an official stamped version of the form. Please make copies of this original form and use it for obtaining consent from participants.**

Approximately eleven months from your initial review date, you will receive a renewal notice stating that approval of your project is about to expire. This notice will give you detailed instructions for submitting a renewal application. If you do not submit a renewal application prior to **January 28, 2009**, your approval will automatically lapse and your project will be suspended. **When a project is suspended, no more research or writing regarding human subjects may be done until the project is reevaluated and re-approved.** I recommend that you respond to these annual renewals in a complete and timely fashion.

This review procedure, administered by the IRB, in no way absolves you, the researcher, from the obligation to immediately inform the IRB in writing if you would like to change aspects of your approved project (please consult our website for specific instructions). You, the researcher, are respectfully reminded that the University's ability to support its researchers in litigation is dependent upon conformity with continuing approval for their work. Should you have questions regarding this letter or general procedures, please contact the Compliance Manager at (773) 508-2689. Kindly quote File #73927, if this project is specifically involved.

With best wishes for the success of your work,

Dr. Raymond H. Dye Jr.
Chair, Institutional Review Board

cc: Nancy Hogan, Ph.D.



Research Services
Institutional Review Board for The Protection of Human Subjects
Lakeside
Lake Shore Campus
6525 N. Sheridan Road | Chicago, Illinois 60626

January 22, 2009

Dear Ms. Patricia Moyle Wright,

Thank you for requesting an extension to IRB file #73927 entitled "Maternal Perinatal Bereavement." After careful examination of the materials you submitted, the Board has approved this project for an additional 1-year period. Below are the details of your approval.

Next Expiration Date: January 28, 2010

Project Status:

- ☒ Enrollment and data collection are on-going.
- ☒ *Consent/Assent form(s) approved and stamped for use during this 1-year approval period. Attached is an official stamped version of the form(s); make copies of this original form and use it to obtain consent.*
- ☐ *Stamped consent/Assent form(s) are not necessary.*
- ☐ Data collection is on-going, but no new participants are being enrolled.
Consent/assent forms are not re-approved for use during the next approval period.
- ☐ Only data analysis and/or writing are on-going.
Consent/assent forms are not re-approved for use during the next approval period.

If the current status of your project is such that no new participants are being enrolled, your consent forms have not been re-approved and are thus invalid. If you wish to change the status of your project and enroll additional participants, you must first seek IRB approval by submitting the consent forms; if approved, the consent forms will be stamped and sent back to you for use.

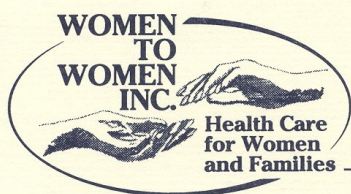
If you wish to amend any part(s) of your project during this one year approval period, you must submit the "Application for Amendment to Research Protocol" form, located on Loyola's IRB website and submit it to the IRB for review (*see web address below). You may not implement any proposed changes until the IRB has approved them. Furthermore, if you complete data analysis and all research activities outlined in your IRB application, prior to your next expiration date, kindly fill out the "Request to Close a Project" form, also located on the IRB website.

Thank you very much for your continued cooperation. If you have questions please feel free to contact me at (773) 508-3018.

Dr. Raymond H. Dye, Jr.
Chair, Institutional Review Board

*download the appropriate form at: <http://www.research.luc.edu/compliance/irb> ; go to the "Forms" section

CC: Dr. Nancy Hogan -Nursing



CHERYL A. FULLER, CRNP
ROBIN GALLAGHER, CRNP

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Kingston, PA 18704

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1-800-532-4404
Fax (570) 714-0473

October 1, 2007

Loyola University
6525 N. Sheridan Road
Chicago, Illinois 60626

To Whom It May Concern;

Patricia Wright, MSN, RN has provided us with a proposal for her study regarding women's experiences with pregnancy loss. We clearly understand the research procedures outlined in the research protocol and approve of Ms. Wright conducting her study utilizing our patient population.

Women to Women, Inc. does not have a formal institutional review process. We do understand that the study protocol will be reviewed by the IRB of Loyola University, Chicago.

If you have any questions, please feel free to contact us.

Sincerely,

Cheryl A. Fuller
Cheryl A. Fuller, PhD, CRNP

Robin Gallagher
Robin Gallagher, DNSc, CRNP

APPENDIX B:
RECRUITMENT MATERIALS

Call for Participants

A local nurse-researcher is currently conducting a
study of unexpected pregnancy loss.

If you have experienced an unexpected pregnancy loss, are at least
18 years of age, can read and speak English, and would like to
participate, please contact :

Patricia Wright, MSN, RN

Phone: (570) xxx-xxxx

Email: wrightp2@scranton.edu

You will be asked to participate in a one-hour interview about your
experience with pregnancy loss.

<p>-----Call for Participants-----</p> <p>A local nurse-researcher is currently conducting a study of unexpected pregnancy loss.</p> <p>If you have experienced an unexpected pregnancy loss, are at least 18 years of age, can read and speak English, and would like to participate, please contact :</p> <p>Patricia Wright, MSN, RN Phone: (570) xxx-xxxx Email: wrightp2@scranton.edu</p> <p><i>You will be asked to participate in a 1-hour interview about your experience with pregnancy loss.</i></p>	<p>-----Call for Participants-----</p> <p>A local nurse-researcher is currently conducting a study of unexpected pregnancy loss.</p> <p>If you have experienced an unexpected pregnancy loss, are at least 18 years of age, can read and speak English, and would like to participate, please contact</p> <p>Patricia Wright, MSN, RN Phone: (570) xxx-xxxx Email: wrightp2@scranton.edu</p> <p><i>You will be asked to participate in a 1-hour interview about your experience with pregnancy loss.</i></p>
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Recruiting Script for Nurse Practitioners

During the office visit, each nurse practitioner reviews the patient's history as part of the routine care provided. Upon noting that a patient has a history of pregnancy loss, the nurse practitioner will invite the potential participant to contact the nurse-researcher for information regarding the study by saying the following:

I see that you have a history of pregnancy loss. A study is currently being conducted in our area on women's experiences with pregnancy loss. If you are interested in participating, please take one of the yellow cards, which includes the researcher's contact information. The researcher will explain the study protocol to you.

We will have no way of knowing who participated, so your decision will have no effect on the services you receive in our office.

APPENDIX C:
PARTICIPANT FORMS

Consent Form

You are being asked to participate in this study of unexpected pregnancy loss, conducted by Patricia Moyle Wright, Doctoral Nursing Student, Loyola University Chicago. You may withdraw from the study at any time without penalty. Choosing not to participate will have no effect on services to you or your family. You are free to refuse to answer any questions. If, during the interview, you become uncomfortable, you have the option to stop and withdraw from the study, or to reschedule.

You will be asked to describe your experiences of pregnancy loss, in your own words. The interview will last approximately one hour. You are free to stop the interview at any time if you become emotionally distressed. You may also be asked for permission to call you at a later time for follow-up or clarification, which would take only a few minutes of your time. If you agree to be contacted for follow-up, please check the box at the bottom of the page.

The interview will be audio recorded. Your interview will be transcribed word for word from the audio recording, and the data will be stored in a locked cabinet. Once this process is completed, the audio recording will be erased. Your name will not appear on the paper or electronic transcripts, reports, or any published papers. However, quotations about your experience with pregnancy loss may be used anonymously in the reports of the study.

There are minimal risks and no direct benefits associated with participation in this research. However, you may experience emotional distress as a result of recounting your experiences of pregnancy loss. If this occurs, you may stop the interview without penalty. You will then be provided with a list of pregnancy loss support resources. Your descriptions of your experiences may contribute to the understanding of the experience of pregnancy loss, which may help health care providers deliver more effective care.

You may call Patricia Wright (570) 941-6484 or Dr. Nancy Hogan, (708) 216-8097, dissertation advisor, to discuss concerns. You may also contact the Compliance Manager at Loyola University Chicago at (773) 508-2689, or Maria Landis, Research Compliance Coordinator, Office of Research Services, University of Scranton, 570-941-6190 with questions about your rights as a research participant.

I freely and voluntarily consent to participate in this study, and will be given a copy of this consent form.

Participant's Name (Print)

Participant's Signature

Researcher's Signature

Date

☐ You may contact me for follow-up at : _____ (phone)

Loyola University Chicago: Lakeside Campuses
Institutional Review Board for
The Protection of Human Subjects

Date of Approval: 1/28/08

Approval Expires: 1/28/09

Consent Form

You are being asked to participate in this study of unexpected pregnancy loss, conducted by Patricia Moyle Wright, Doctoral Nursing Student, Loyola University Chicago. You may withdraw from the study at any time without penalty. Choosing not to participate will have no effect on services to you or your family. You are free to refuse to answer any questions. If, during the interview, you become uncomfortable, you have the option to stop and withdraw from the study, or to reschedule.

You will be asked to describe your experiences of pregnancy loss, in your own words. The interview will last approximately one hour. You are free to stop the interview at any time if you become emotionally distressed. You may also be asked for permission to call you at a later time for follow-up or clarification, which would take only a few minutes of your time. If you agree to be contacted for follow-up, please check the box at the bottom of the page.

The interview will be audio recorded. Your interview will be transcribed word for word from the audio recording, and the data will be stored in a locked cabinet. Once this process is completed, the audio recording will be erased. Your name will not appear on the paper or electronic transcripts, reports, or any published papers. However, quotations about your experience with pregnancy loss may be used anonymously in the reports of the study.

There are minimal risks and no direct benefits associated with participation in this research. However, you may experience emotional distress as a result of recounting your experiences of pregnancy loss. If this occurs, you may stop the interview without penalty. You will then be provided with a list of pregnancy loss support resources. Your descriptions of your experiences may contribute to the understanding of the experience of pregnancy loss, which may help health care providers deliver more effective care.

You may call Patricia Wright (570) 941-6484 or Dr. Nancy Hogan, (708) 216-8097, dissertation advisor, to discuss concerns. You may also contact the Compliance Manager at Loyola University Chicago at (773) 508-2689, or Maria Landis, Research Compliance Coordinator, Office of Research Services, University of Scranton, 570-941-6190 with questions about your rights as a research participant. I freely and voluntarily consent to participate in this study, and will be given a copy of this consent form.

Participant's Name (Print)

Participant's Signature

Researcher's Signature

Date

☐ You may contact me for follow-up at : _____ (phone)

Loyola University Chicago: Lakeside Campus
Institutional Review Board for
The Protection of Human Subjects
Date of Approval 1-28-09
Approval Expires 1-28-10

Pregnancy Loss Resources

Local Resources

Empty Arms Support Group

- Run by XXXXXX Health System
- Provides support in a group setting for those who have suffered any type of pregnancy loss or stillbirth.
- Meets on the first Wednesday of each month. Registration is required.
- For more information or to register, contact Doris or Pearleen at (570)xxx-xxxx

Infant Loss Support

- Run by XXXX, LSW, at the XXXX Birthing Suites
- Specializes in perinatal bereavement support
- Provides support resources following perinatal loss, including referrals for individual counseling, as needed
- For more information, call (570) xxx-xxxxx

Individual Counseling

XXXXXXXX, Ph.D., APRN-BC

XXXXXX Psychiatric Services

XXXXXX Kingston

For appointment, call (570) xxx-xxxx

Web-Based Resources

American Pregnancy Association

- Web site: <http://www.americanpregnancy.org/pregnancyloss/>
- Provides information on the types and causes of pregnancy loss, medical care following pregnancy loss, and emotional support after loss

Share Pregnancy and Infant Loss Support, Inc.

- Web site: <http://www.nationalshareoffice.com/>
- Provides information, support packets, and resources for parents who have experienced pregnancy loss, stillbirth, or neonatal losses
- Online chat room provides regularly scheduled support meetings
- Newsletters are available on a variety of topics related to perinatal loss
- Support information and resources are available in English and Spanish

The Compassionate Friends

- Network for parents who have lost a child of any age
- Web site for information on stillbirth, miscarriage, and infant death:
<http://www.compassionatefriends.org/brochures/stillbirth.htm>
- Newsletters and grief support information available
- Information on local support groups accessible online

Interview Guide

1. Please tell me about your pregnancy and your loss.

Probe Questions:

- a. What kinds of things do you think nurses and doctors can do to help women who experience pregnancy loss?
- b. What kinds of things helped or hindered your coping with the loss?
- c. Do you feel that you have changed as a result of your loss?
- d. Do you feel that your relationships with others changed as result of your loss?

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VITA

Patricia Moyle Wright completed her undergraduate nursing education at Misericordia University in Dallas, Pennsylvania, and worked as a medical-surgical and hospice RN. She later completed a Master of Science of Nursing degree at Misericordia University, with a clinical specialization in adult health and a functional specialization in education. Ms. Wright worked as a medical-surgical clinical nurse specialist, where she sought to bring palliative care initiatives into the acute care setting. Throughout the doctoral program at Loyola University Chicago, Ms. Wright focused on end of life issues, such as grief and bereavement. She published several peer-reviewed articles while in the program, and received several grants. Additionally, she was honored to receive a scholarship from Nurses' Educational Funds, Inc. for the 2008-2009 academic year. Ms. Wright currently serves on the boards of the Pregnancy and Infant Death Alliance (PLIDA) and the Domestic Violence Service Center in Wilkes-Barre, PA. She is an assistant professor of nursing at The University of Scranton, where she teaches undergraduate and graduate nursing courses, and hopes to prepare the next generation of nurses to support patients and families who are facing end of life issues and loss.

DISSERTATION APPROVAL SHEET

The dissertation submitted by Patricia Moyle Wright has been read and approved by the following committee:

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The final copies have been examined by the director of the dissertation and the signature which appears below verifies the fact that any necessary changes have been incorporated and that the dissertation is now given final approval by the committee with reference to content and form.

The dissertation is therefore accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

March 3, 2010
Date

Nancy Hogan
Director's Signature